

Invisible Disability*

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I. INTRODUCTION

If we look closely at the notion of “invisible disability” and consider what it might mean to describe a disability as “invisible,” we will be able to understand the source of some of the presuppositions—and confusions—that underlie people’s unreflective views about disability. Engaging in such an inquiry may also heighten our awareness of inequities and indignities that are routinely visited upon persons with disabilities, and help us untangle theoretical and moral quandaries that have confounded philosophers, disability studies scholars, and disability rights advocates.¹

The examination of the notion of invisible disability is also worth undertaking in its own right. There are many individuals with conditions, illnesses, and structural or biomechanical anomalies that are life limiting but not readily discernible to others. People who suffer from severe depression, chronic pain, or posttraumatic stress disorder (PTSD); people who are violently allergic to common household chemicals; those who have a seizure disorder, chronic fatigue syndrome (CFS), or severe fibromyalgia; and those who have sustained a mild traumatic brain injury (MTBI) may all appear “normal” to people with whom they

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1. It is helpful in the latter regard to look at the Americans with Disabilities Act (ADA) 1990, and at the criticism of both the foundations and applications of central notions. See Leslie Pickering Francis and Anita Silvers, eds., *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions* (New York: Routledge, 2000).

have casual interactions.² Yet they may still be disabled: the quality of their lives may be no less profoundly or adversely impacted by these conditions than is the quality of life of those whose disabilities are more obvious: something can “substantially limi[t] one or more of the major life activities” of an individual even if other people cannot easily identify the source of such limitations in casual interactions with that person.³ People whose disabilities are not generally perceived by others do not, for that reason alone, find it easier to minister to themselves or to engage productively and effectively in the world without having to endure pain, discomfort, and exhaustion. There is no reason to believe that the invisibility of a disability itself necessarily lessens its impact or makes the disability less serious.

Some commentators believe that the facial invisibility of a disability must mitigate the impact of disability, since it enables a person to escape the sort of stigmatization that attaches to individuals whose disabilities are visible.⁴ I believe that such a conclusion is unwarranted and that a careful exploration of invisibility and invisible disability will enable us to arrive at a better understanding of why this is so. Though not as easily stigmatized in obvious or familiar ways, persons with invisible disabilities are subject to forms of rejection, humiliation, and social disapproval that are importantly similar. When individuals are not “seen” as disabled, it can be more difficult for them to secure the assistance or accommodation they need to function effectively. Because they are not identified as disabled, those whose disabilities are invisible must often bear the burden of securing the assistance they require. This may require them to approach strangers to inform them that they are disabled and to explain what sort of help is needed. Often, it is not sufficient for “invisibly disabled” persons to reveal that they are disabled and provide information about their “special needs.”⁵ Those whose disabilities are invisible may also have to convince other people that they really are *disabled*, not seeking some special—unfair—advantage: thus, what they must do is meet a burden of proof. They thus face a double bind: either they forgo the assistance or accommodation they need—

2. Both what I mean and why I choose to characterize these as “invisible” rather than as “nonobvious” disabilities will be explained below. See especially Sec. II, which discusses our human paradigm and the primacy it accords to meeting able-bodied standards.

3. ADA, sec. 3, 2a.

4. Mark Kelman and Gillian Lester, *Jumping the Queue: An Inquiry into the Legal Treatment of Students with Learning Disabilities* (Cambridge, MA: Harvard University Press, 1997). I am grateful to David Wasserman for calling my attention to this.

5. I find this to be a condescending and offensive term, which is why I flag it with scare quotes. Why should the provision of a ramp be seen as meeting a “special need” rather than as meeting the very widespread and unspecial need for access? Unfortunately, it is term that is widely used.

and thus suffer the consequences of attempting to do things they may not be able to do safely by themselves—or they endure the discomfort of subjecting themselves to strangers’ interrogations.⁶ For those who are disabled, not receiving needed assistance is not merely disappointing or frustrating; it may be an insuperable obstacle or a risk to health or life. And being forced to endure a stranger’s cross-examination can be intensely stressful. Stress is unpleasant for everyone, of course, and it can wear anyone down. But the increased fatigue and decreased immunity that result from stress are likely to have a more profound effect on the health and well-being of people who are disabled.⁷ In Section VI, I shall explain in more detail how having to reveal that one is disabled and having to make requests for assistance or accommodation that are often met with skepticism and hostility can visit steep psychic and moral costs upon persons with invisible disabilities.

In contesting the claim that things are *de facto* less difficult for those whose disabilities are invisible than they are for those whose disabilities are visible, I am not asserting that appearance-based stigmatization does not have serious consequences or ones that are less significant than people have supposed. Nor am I controverting the claim that “physical conditions” or “organic causes” of disability contribute significantly to the suffering, effective disadvantage, and discrimination that disabled persons face. In fact, I think that the very supposition that we can distinguish between bodily or organic causes of disabled persons’ suffering, stress, and disadvantage, and the broader social conditions that shape the experiences of suffering and disadvantage—or even apportion the weight of their respective contributions—is questionable, both as theory and as policy.⁸ If we are interested in trying to understand disability, and in trying to formulate disability policies that are both adequate and morally sensitive, we would do well to recognize that energy expended in the attempt to isolate “the facts” of disability from

6. The bind they are in is actually more complicated than this. I will explain how this is so in Sec. VI.

7. For an excellent, accessible discussion of some of the physical effects of stress, see Robert Sapolsky, *Why Zebras Don’t Get Ulcers* (New York: Freeman, 1998). See also Sapolsky, “Measures of Life,” in his *The Trouble with Testosterone* (New York: Touchstone, 1998), 63–74.

8. The claim is analogous in this regard to the claim about genes and the environment: in both cases, although they can be spoken of distinct factors for analytic purposes, the “purely physical” (or “biological” or “genetic”) and the “social” (or “cultural” or “environmental”) operate interactively. As geneticists and developmental biologists remind us (often to no avail), “all traits . . . are caused by dependent interactions of genes and environments. . . . Moreover . . . it is theoretically impossible to determine how much of a trait is caused by genes and how much is caused by environmental factors” (David S. Moore, *The Dependent Gene* [New York: Holt, 2001], 8). See also Richard C. Lewontin, “The Analysis of Variance and the Analysis of Causes,” in *The IQ Controversy*, ed. Ned Block and Gerald Dworkin (New York: Pantheon, 1976), 179–93.

the prevailing moral and social attitudes that influence our understanding of the meaning and salience of these facts is energy misdirected. In the body of this article, I will provide some explanation and defense of this claim. Whether or not that analysis is compelling, I believe that the process of considering it will provide support for my central thesis: that acquiring a better understanding of invisible disability will enable us to attain a better understanding of disability and gain greater insight into the problems that face disabled people in our society.

The class of conditions that may be plausibly described as “invisible disabilities” is both large and diverse. I shall say more about this in Section VI. Here I wish only to point out that the fuzziness of the category is partly a consequence of the fact that the class of things that can be characterized as disabilities is large and diverse: when things are identified primarily by what they are not, this is often the case. It is also partly a consequence of the fact that the characterization of something as invisible is also contrastive and relative. When we say that something is invisible, we do not mean to claim that the thing is invisible to everyone, or to anyone in any circumstances. What we do mean is that it is (or would be) invisible to a particular set of perceivers under a particular set of conditions. When we say that something is invisible, we are generally making a tacit comparison between this thing and others of the same kind that we think are not invisible, and implying that invisibility is not the norm for things of that kind. On a walk through a meadow, I may say that the field mice are invisible, even though both my companion and I know that they are certainly visible to the hawks that circle the field, and to us when they visit the kitchen for a midnight snack. What this reveals is that judgments of invisibility are not just relational and context dependent, but more deeply normative. To say that something is invisible *tout court* is to invoke the viewpoint of perceivers relevantly like oneself, ones presumed to have the visual acuity of human beings. It accords primacy to those perspectives and experiences thought to be “normal” for human beings. Such a remark is generally uncontroversial: we are usually talking to other humans and justified in assuming that we share human abilities and a human perspective. But it is not, therefore, one whose meaning is transparent. As I shall explain in the next section, the content of the standards of “normalcy” that are being invoked is neither clear nor obvious. The standards are not simple statistical ones; they are more abstract and idealized constructions whose precise content and parameters are difficult to specify with precision. Even in this simple case, we recognize that the standard being invoked—roughly, the possession of 20/20 vision with correction—may not in fact be one that is realized (or realizable) by the individual we are speaking with, or indeed, many of the people who walk through this meadow. Myopia is not a rarity in human beings.

The notion of disability is also both relative and contrastive. To say that someone is disabled in some way is not simply to say that he or she cannot do something, or some set of things: it is rather that he or she cannot do things that the speaker supposes individuals of that kind are supposed to be able to do.⁹ I shall explore some of these presuppositions in Section II. Here we need only note that whether the standards being tacitly invoked are taken to be universally applicable norms of “species-typical” functioning, or ones that are relativized to more narrowly specified groups of humans, the characterization of something as a disability is not purely descriptive. Even when we take the standards they invoke to be obvious and uncontroversial, it is important to recognize that disability claims are appraisals and that they involve judgments that are norm-relative and norm-dependent in complex ways.

My hope is that the investigation of “invisible disability” will deepen our appreciation of the significance of the fact that assessments of disability are norm-bound in this way and will enable us to appreciate that they are norm-relative and norm-dependent in more diverse and complex ways than many discussants have supposed. Once we understand that the identification of an individual as disabled does not involve only the invocation of a set of purely physical or “objective” standards but also a range of norms that invoke purposes, policies, and institutions, this should help us both to understand why it is a mistake to suppose that the determination of whether someone is disabled is a purely factual matter, or a simple one, and to appreciate that such assessments have a verdictive character as well as a descriptive one. This, in turn, may have important implications with respect to how we appraise disability policies, including the ADA, and how we approach problems of application.

II. HUMAN PARADIGMS AND THE PRIMACY OF ABLE-BODIED STANDARDS

As I shall be using the term, a society’s ‘human paradigm’ both embodies and expresses its beliefs about what human beings are and what (in that particular society) people think they ought to try to be. The human paradigm that a society embraces thus shapes or defines the character of life in that society in salient respects. It directs individual choices and shapes institutions. It also gives substance to people’s understanding of

9. There may seem to be some universal abilities and disabilities. But the fact that we adjudge someone who cannot walk, e.g., as disabled does not show that the assessment is purely descriptive, but rather that we view walking as normative for most groups of humans. We do not view infants who cannot walk as disabled (though we may think that they are handicapped by their inability to walk): a baby who cannot walk is no different from virtually all other babies. See Sec. II for further discussion of this point.

fulcral concepts like wellness and illness, health and disease, and ability and disability, and directs their application of them. It is hard to characterize such things with precision or to present a compelling argument for the decisive superiority of one particular characterization, but I believe that the way we view disability has been profoundly affected by the fact that our society's human paradigm treats being able-bodied as both normal and normative and accords a special primacy to being (and being seen to be) able-bodied.¹⁰ To conform to our society's vision of what a human should be, one must be (thought to be) able-bodied.

It is not sufficient, and it is not necessary in all cases. But it is generally thought to be necessary.¹¹ We do not think just that it is a

10. As will emerge, it is not entirely clear what we think it is to be able-bodied, nor is it clear that we mean just one thing, or the same thing in different contexts. It would be a mistake for me to try to clarify the notion further, though, since I think that the clarification would be largely stipulative. In using the term and in speaking of 'able-bodied standards' I am trading on the supposition that people are likely to think they know what they mean when they say that someone is able-bodied, and I am reminding us that there are norms at work—standards—not mere descriptions. The concept has structural, functional, and aesthetic components and presupposes a certain view of the relation between them. A person who meets able-bodied standards looks like he or she can do the things we suppose humans of that sort are capable of doing—or expect them to do. The notion is not purely functional, since a person may be able to do what others can do even if he or she has an anomalous bodily configuration. People who are born without a hand generally learn to do with one hand (and two legs) most—perhaps all—of the things that they need to be able to do. But even the most deft of congenitally one-armed persons would probably not be described as "able-bodied." (Insofar as she was, it would be a term of praise, not a description.) Part of being thought to meet able-bodied standards is being thought to be able to do the things humans are usually thought to be able to do (yes, there is a circularity here), but that is not the whole of it. There is a presumption that those who look like they ought to be able to do what we expect humans to do are indeed able-bodied. The presumption is rebuttable: someone who had sustained severe internal injuries, etc., that did not get reflected in his or her appearance might not be described as able-bodied, but this would be likely to happen only after the person's circumstances had been explained. The presumption that those whose bodies look "normal" (yes, there is circularity here again) are able to do what normal people can do resounds at deeper levels. There is great suspicion of claims that one cannot do something (e.g., lift a light weight) when there is no clear physical sign of inability or disability. As I shall argue, this helps explain why claims of mental illness, and more generally of the presence of conditions that involve symptoms that are psychological, are highly suspect. What I will mean by 'S meets able-bodied standards' is thus something like the following: S has all of the parts that normal humans have and does the things with his or her body that we take to be things that those who have working parts can do. Clearly, it is a term of art.

11. As I see it, it is important to recognize that the existence of extraordinary individuals—the ones who manage to overcome formidable obstacles—does not present a challenge to the claim that something is generally expected of everybody. It is usually also a disservice to persons with disabilities for the media to publicize stories of amazing individuals who have managed to do the incredible x (fill in the blank) despite being disabled. People tend to overlook the fact that those individuals—and the sort of economic and social support they have—are not the norm. Their stories may be inspirational, but

good thing for people to meet able-bodied standards; we also assign great and special importance to their doing so. In our society, many people choose to do things that compromise the realization (and sometimes even the possibility of the pursuit) of other things they value in order to meet able-bodied standards. While a person must often neglect the pursuit of one good to pursue another, this is not merely a case in which we are faced with a choice between competing goods; the situation is more complicated. Because we assign so much importance to meeting able-bodied standards, we sometimes compromise, or even sacrifice, other things we prize even to attain the mere appearance of being able-bodied.

Our assigning primacy to meeting able-bodied standards should not be construed as a reflection of our assigning great importance to being healthy. Still less should meeting able-bodied standards be thought to be a precondition of being healthy or a constituent of health. A person can be healthy without being able-bodied, and someone who meets able-bodied standards can in fact have medical problems that are serious, but nonobvious. We may best appreciate this point by taking note of the fact that a number of the people who live in our society choose not only to expend time, energy, and money in order to appear to meet able-bodied standards but also to do things that may compromise their health—and risk their life—to do so. Those who elect to undergo cosmetic surgery submit to procedures that may involve the use of general anesthesia, and ones that involve the performance of a number of invasive procedures on different areas of the body.¹² In so doing, they are both choosing to run grave risks, and running them not to become healthier or more vigorous but merely to appear to be. Neither the age of a person's internal organs nor the functionality of a person's body is affected by cosmetic surgery that makes the person

they seldom present a picture of a more universally attainable achievement. Still less do they present a usable template for them. Anita Silvers's remarks about compensation also provide an important, and sensitive, reminder that it is not through the use of any simple or straightforward sort of "compensation" that we can hope to "level the playing field" to enable disabled persons to succeed on the society's terms: "Adjusting the environment so anomalous individuals can better flourish can be as compensatory as leveling them. . . . Wherever strategies that equalize the amount of opportunity individuals have available rather than homogenize the kinds of opportunities they can access are feasible, there is even less reason to suppose that restoring anomalous individuals to normal modes of functioning is a better instrument of justice than enhancing the effectiveness of their anomalous modes" ("A Fatal Attraction to Normalizing," in *Enhancing Human Traits: Ethical and Social Implications*, ed. Erik Parens [Washington, DC: Georgetown University Press, 1998], 95–123, 121).

12. Recently, it was widely reported in health news that general anesthesia may have deleterious effects on patients' health for a year (or more) after the surgery that necessitated its use. If this finding is confirmed, it should have an impact on how people view elective surgeries.

appear younger: looking like one is able-bodied does not make one more able-bodied, nor does it thereby make one healthier. The human paradigm that we embrace underwrites our attaching so much importance to meeting able-bodied standards that many of us are willing not only to forgo but also to jeopardize the other things we value highly merely to appear to meet them. This is very strange. It also seems to be self-defeating or to uncover a fundamental incoherence in our human paradigm.

But this appraisal is too simplistic. What it overlooks is that there is not only a functional dimension to conforming to able-bodied standards but also an aesthetic one, and that it is a shallow good in at least two respects. First, it is a good whose presence or absence can generally be more easily ascertained by others than the possession of many of the virtues, talents, and achievements that figure in our human paradigm (e.g., having meaningful and fulfilling work or being embedded in a rewarding and complex web of human relationships). Second, it is one that can often be acquired by mechanical or artificial means. Even if one cannot actually come closer to meeting able-bodied standards, one can—at least to some extent—bring it about (or have it brought about) that one looks like one meets able-bodied standards. We can do things that change our appearance, and only our appearance. And we can hire people to make the sort of changes that we ourselves cannot effect. We cannot do the same with many virtues and talents, or with many other human goods. It might thus seem to make sense for people to devote considerable effort to trying to appear to meet able-bodied standards: doing so would enable them both to lay claim to exemplifying (at least that part of) the human paradigm and to back up that claim by displaying the fact to others. Moreover, since we know that we are prone to the “halo effect”—once we have seen virtue, excellence, or achievement in one area, we are more likely to assume that it is present in other areas—both the assignment of primacy to able-bodied standards and our attaching so much value to appearing to be able-bodied make better sense.

They make *better* sense, but I do not think that they make *good* sense for us now, at the start of the twenty-first century. By continuing to assign so much importance to meeting (and appearing to meet) able-bodied standards, we run the risk of both neglecting and subverting other elements of our human paradigm, including some that there are now more compelling reasons for us to value more than people did several generations ago. Thus, if we continue to assign primacy to meeting able-bodied standards, there is reason to think that this will result in our living lives that are less good by our own lights.

In earlier eras, being able-bodied might well have been a precondition both of achieving a reasonable standard of well-being and of

being able to pursue and achieve most of the other things that figure in our human paradigm. Not that long ago, there was a tighter connection both between being able-bodied and being healthy, and being able-bodied and being economically self-sufficient. Since much work was physical, or involved a large physical component, and the conditions of employment were grueling, men who were not able-bodied could not be confident of being able to find employment to support themselves and their families. And women who were not able-bodied could not be confident of being able to survive unless they could find husbands who would support them: a married woman needed to be able to withstand the rigors of childbirth and household labor, which involved heavy physical work. A man who did not appear to be able-bodied would probably have had a harder time obtaining secure employment, and a woman who did not appear to be able-bodied would probably have had a harder time finding a husband to support her. Both being able-bodied and appearing to be able-bodied would thus have been extremely important. Though it is a bad idea to make inferences from mere appearance to capacity or incapacity—or to health and unhealth—in days in which people did not have elaborate means of making themselves appear to be able-bodied when they were not, the inference that someone who looked able-bodied actually was able-bodied was a more reasonable one.

But in a society characterized by the widespread implementation of a multitude of labor-saving technologies and sophisticated medical treatment, it is no longer true that most men support themselves by doing manual labor, that most conditions of employment are physically grueling, or that those who cannot endure them have no other options. Nor is it true that there is a tight connection between meeting able-bodied standards and being healthy or that women's economic security is so heavily dependent on their ability to attract husbands to support them.¹³ Thus, neither being able-bodied nor appearing to be able-bodied can now plausibly be held to be a precondition of being able to meet one's more basic human needs or of attaining the other goods embodied in our human paradigm.

It is also clear that our continuing to assign so much importance to meeting able-bodied standards poses a greater risk of compromising other human goods that make up our human paradigm than it did several generations ago. We live much longer lives now; there is thus a

13. To say this is not to claim that women's (actual or perceived) self-sufficiency in our society is equal to men's. There are, of course, many factors that contribute to women's comparatively greater dependency on men, especially among those women who are not middle class. There are, e.g., disparities in earning potential, and in educational opportunities. The point is merely that both for women and men, well-being is now much less tightly hinged to meeting (or appearing to meet) able-bodied standards.

larger portion of our lives during which we are likely to fall short of able-bodied standards, and a larger part during which we are likely to appear to fall short of them. Coincidentally or not, during this portion of life—this stage of later life—our continued well-being is affected more by our prior development of talents and virtues, and our involvement in a myriad of significant human relationships, than it may be at other times. We are more likely to be able to live long lives that are good, happy, and admirable if we accorded these things due weight before we reach old age, and more likely to do so if we accord them value in old age.

A society that attaches great importance to meeting able-bodied standards is thus one that is likely to fail its older members—and our future selves—in several related ways. Insofar as an aging body is perceived as one that is *de facto* a less able body (independent of the person's actual state of health), the society is likely to view older people as being further from the human paradigm simply because they are older. In simple terms, it is likely to devalue them and, thus, to attribute less importance to meeting their needs than it does to meeting the needs of individuals who come closer to exemplifying its human paradigm: those who it thinks meet able-bodied standards or could more reasonably hope to be able to do so. Moreover, because people internalize the values of their society, even when older citizens find their lives fulfilling in ways they deem to be important, they would be more likely to devalue themselves and to see themselves as wanting or deficient simply because they fell short of able-bodied standards. It thus seems reasonable to suppose that they would be less likely to try to advance the view that the society should assign more weight to meeting the needs of those who do not meet able-bodied standards or to configure itself to accord due weight to the value of living a life whose focus is elsewhere than on meeting these standards. If this is so, then our continuing to attribute so much importance to meeting able-bodied standards may both subvert our human paradigm and bring it about that people disvalue lives that are, in fact, good lives. And if this is so, they will live lives that are much less good than they could have been.¹⁴

Our continuing to assign great importance to meeting able-bodied standards privileges one class of achievements and one class of goods over the others that comprise our human paradigm and seem to have no less strong a connection to human well-being and flourishing. In a society in which our meeting able-bodied standards is no longer so tightly linked to our ability to meet basic human needs or to realize

14. Here we must bear in mind Silvers's reminder that accommodation of "anomalous individuals" is not homogenizing and that certain well-placed enhancements may work better than mere accommodation ("A Fatal Attraction to Normalizing").

other important goods, continuing to do this seems irrational. When we reflect on the fact that we now live longer, and thus are likely not to meet narrow able-bodied standards for a larger portion of our lives, on the consequences of our seeing ourselves as inferior simply because of that fact, and on the significance of our needs being seen as less important by our society, we should be able to appreciate that this is no small irrationality, nor is it simply irrationality. It is a choice that is profoundly morally problematical.

Of course, not only those individuals who live longer lives are unable to meet able-bodied standards. Many other people cannot do so either, most notably many of those who are disabled. Moreover, as medical knowledge and technological sophistication increase, there is good reason to believe that the number (and proportion) of individuals who do not meet able-bodied standards will increase. And there is no reason to suppose that the lives of people who do not meet narrow able-bodied standards will have to be less meaningful, less valuable, or less productive because they are not able-bodied. As a society, we clearly possess both the will and the ability to use medical and technical means to treat things we could not even imagine treating fifty years ago. We can now treat a greater range of congenital anatomical anomalies, serious illnesses (acute, chronic, and recurrent), and traumatic injuries. We have developed both increasingly sophisticated prostheses and surgical and pharmacological interventions that reduce the impact of these illnesses and anomalies, as well as social supports that alter our perception of their meaning.¹⁵ Nor do we gauge the success of such treatments and interventions by the degree to which they enable individuals to meet a narrow able-bodied paradigm (or even to appear to do so); we assess their value and effectiveness in terms that are robustly personal rather than narrowly physical. As medical knowledge and technical skill continue to grow, the scope of the illnesses, anomalies, disorders, and injuries that can be effectively treated will continue to grow, and, presumably, so will the number of individuals who do not meet narrow able-bodied standards. It is thus reasonable to suppose that our continuing to embrace a human paradigm that accords so much weight to meeting able-bodied standards would result in the systematic devaluation of a large and ever-increasing portion of the populace and their achievements. There is thus not only no good reason to continue to attach so much primacy to meeting able-bodied standards, there is also good reason not to do so.

15. The list of possible examples here is a long one: babies with anatomical deformities like spina bifida, children who develop cystic fibrosis (the projected life span of such children has increased dramatically within the past twenty years), people with diabetes or seizure disorders, and those who have sustained traumatic brain injury.

But such a human paradigm is not problematical merely because it is outdated, or because it seems to embody a view of human worth that is morally flawed. There are also reasons to doubt whether it is coherent, and whether it can be coherently applied. Explaining what these are will take some time, but it is worth it.

Those whose human paradigm accords primacy to able-bodied standards generally make three connected assumptions that bear on their understanding of disability. The first is that it is normal for humans to be able-bodied. The second is that a person's disability is a consequence of (or results from) his or her not being able-bodied. The third is that it is principally their abnormality (or their not being able-bodied) that explains why those who are disabled suffer disadvantage in society: both the suffering and the disadvantage of those who are disabled are natural in the sense that they are consequences of the fact that their bodies are defective in certain respects.

Together, these views underlie what I will call "the dominant ideology," which can be roughly summarized as the view that the pain, suffering, frustration, and disadvantage that disabled persons experience in our society is a natural consequence of the fact that they are disabled. Widespread subscription to some form of this dominant ideology is one of the main supports of the widespread reluctance to endorse policies of accommodation that would make life easier and better for those with disabilities (and for those who interact with them). All three of these assumptions and the dominant ideology they support are not merely problematical in moral terms but also beset by serious conceptual confusions.

Before we can assess the truth of the claim that it is the abnormality of those who are disabled rather than a given society's choice of (possibly objectionable) social policies and practices that principally explains why individuals with disabilities suffer the pain, frustration, and disadvantage that they do in that society, we need to understand what it means in general terms to say that an individual's having (or failing to have) a certain trait is a species of abnormality. But clarity is not easily achieved here. Even among those who are thought to be experts in such things—including biologists, anatomists, anthropologists, ethologists, ecologists, and physicians—there is a good deal of disagreement both about which members of a population are properly classified as normal, and about what it means to say that certain members of a population are physically or functionally normal. Individual organisms do not develop traits and abilities in a vacuum, nor can their development always be merely observed (and not affected) in the carefully controlled environment of a laboratory. What traits a particular organism develops and the circumstances under which the organism manifests them depend on the complex and subtle interplay of many factors. The judgment that some trait

is abnormal—or that the individual who possesses such traits is abnormal—embeds a hypothesis about how the individual came to have the trait in question, which in turn involves a determination of which of the conditions that were causally necessary for the trait's emergence should be regarded as most salient.¹⁶ Determinations of the etiology of a trait thus involve reference to other members of the population and tacit assumptions about the “normalcy” of the organism's environment. Neither the fact that an individual organism is different from others in the population—or others we have thus far encountered—nor the fact that it exhibits different behaviors is itself sufficient reason for thinking that that individual is not normal. The determination that something is (or is not) normal has an adaptive dimension and draws upon conjectures about what was necessary for the survival of the individual in this environment.¹⁷ The judgment that an organism is abnormal (in some respect) is thus not a mere report of structural or functional irregularity, but one that is relativized to judgments about the individual's environment and the adaptive value ascribed to the irregularity.

It is clear that how *human* organisms develop depends on both physical aspects and social features of their environment. In the case of humans, the specification of what constitutes a “normal environment” includes a presumption of the existence of culture and the complex social and educational institutions embedded in it. We do not suppose that normal human traits are all and only those that humans would develop in the wild or in some hypothesized state of nature (even if we think that we can make meaningful conjectures about what those traits would be).¹⁸ And again, the judgment that something is abnormal is relativized to the environment, and sometimes to the presumed beliefs and desires of the individual who is being adjudged abnormal, in a number of different ways. For example, we consider it normal for humans who live in Western industrialized societies like ours to be able to read: we expect adults to do it, we think that most people can do it, and we recognize that those who cannot (or simply do not) do so are generally disadvantaged. But it cannot be said simply that an individual's not reading (or not speaking, not walking, etc.) is a disability or that it constitutes evidence of the existence of one. An individual who does not read, speak, or walk may simply not want to do these things. We

16. See Robert Sapolsky, “The Trouble with Testosterone,” in *The Trouble with Testosterone*, 149–59; Moore, *The Dependent Gene*; Richard C. Francis, *Why Men Won't Ask for Directions* (Princeton, NJ: Princeton University Press, 2004); Jonathan Marks, *What It Means to Be 98% Chimpanzee* (Berkeley: University of California Press, 2002). Also see n. 8 above.

17. These beliefs have a counterfactual element: they often involve conjectures about how the individual would have developed in different circumstances, ones in which, ex hypothesi, this individual never found himself or herself.

18. Marks, *What It Means to Be 98% Chimpanzee*, chap. 7.

cannot infer disability merely from the fact that someone does not do what everyone else does. We presuppose the aptness of a certain sort of explanation for the individual's not doing it: the individual does not do it because he or she cannot do it.¹⁹

Of course, we might well suspect that an individual who did not want to read, speak, or walk was disabled. We believe that it is important for people to do such things, and the way that our institutions are structured presupposes that most adults will do them. There is thus generally significant disadvantage attaching to failures to read, walk, or speak, so people do not generally choose not to do these things. Moreover, when we think that an individual does not do them because he or she chooses not to, we are likely to conjecture that there was some psychiatric disorder that posed an impediment to the individual's choice or accounted for the individual's refusal to do what everyone else did, and what it was clearly disadvantageous for this individual to not do. But a diagnosis of extreme paranoia or the identification of massively self-destructive tendencies stemming from a character disorder would not necessarily provide us with grounds for supposing that the individual could not read. Nor would the diagnosis of extreme social anxiety or selective mutism provide us with grounds for thinking that someone could not speak. We might see these disorders as disabling, but we would then be seeing the individual's not reading or not speaking as a symptom of disability, not as itself a disability.

I have tried to show how the judgment that some observed trait constitutes an abnormality involves a complex—generally unexamined and unarticulated—set of assumptions. The claim that an observed abnormality constitutes a *disability* involves still more presuppositions and is even more vulnerable to challenge. The judgment that something is a disability presupposes the aptness of certain sorts of descriptions of the trait one is identifying as abnormal. For example, to claim that not reading or not speaking is a disability (or that it provides evidence of the existence of one), we need to be able to defend the claim that the individual's failure to walk or speak stems from the inability to walk or speak, rather than a choice not to do these things. Disability assessments also presuppose views about the etiology of the individual's inability to read or speak: we must think that it developed in the sort of "normal" human environment that we can characterize as adequate. In the case of the inability to read, that would involve (something like) a belief that this individual had received the sort of nurturance and education that would have made the acquisition of reading skills something it was

19. Or the individual cannot do so without great pain, etc. I shall henceforth omit the qualification, but it should be recognized that its (essential) vagueness makes even this seemingly simple and uncontroversial characterization difficult to apply.

reasonable to expect most individuals to acquire in those circumstances. If we know that this particular individual's environment was clearly not normal, or adequate, we are reluctant to say simply that the individual cannot read or that his or her not being able to read is properly characterized as a disability. (We can and do say that the individual is disadvantaged, perhaps even that he or she has been damaged.)

Insofar as judgments of disability are thought to be predicated upon assertions of abnormality, when the parameters we have, or know about, do not allow us to make unequivocal assertions of abnormality—or where, as in this case, they seem to license conflicting assessments—we hesitate to claim that something is a disability. It is normal for children to learn to read by age ten, but not normal for them to learn to read if they were not given attention and nurturance or provided with stimulation or reading material. Judgments of normality (or abnormality) are complex and equivocal. It is thus not unusual for us to be in situations in which we cannot say with confidence whether something should be classified as abnormal. A parent whose child falls in the lowest decile in height at age two may be told that it is normal for his or her child to be abnormally short: this seemingly inconsistent remark makes sense to us because we understand that there are different and complex indices of normality at work here. (For example, the physician may be taking account of the height of the child's parents or drawing upon knowledge of the child's siblings' growth patterns: what is normal in one respect may be abnormal in others.)

The terrain here is dense; the salient point is that the sort of judgments of abnormality that are taken to provide grounds for claiming that an individual is disabled—not merely odd or disadvantaged by circumstance—are thick ones. It is not simple observation of individuals' behavior that we draw upon, but interpretations of the meaning of that behavior and the motives that underlie it, ones that often involve tacit reference to the individuals' presumed beliefs and desires and assessments of the adequacy of their environments. Such interpretations are fallible in a number of ways. We know that the content of what a person comes to believe and desire is strongly influenced by the details of his or her acculturation and the social circumstances surrounding his or her development. We understand that the details of our own acculturation may interfere with our being able to produce a sympathetic interpretation of the behavior of a person from another culture. This confers a certain opacity on (and real complexity to) our assessments of whether a given anomaly constitutes an abnormality, and on whether it can be said to be a disability. It is not a simple matter to determine whether a person is normal or to determine whether an ostensive abnormality is properly characterized as a disability. Assessments of disability that are founded on the supposition that the disabling trait is an

abnormal one are both more complex and more controversial than those who embrace the dominant ideology seem to suppose.

How humans develop is affected by what sort of nurturance and protection they have received, what sort of diet they have had, what sort of education they have received, what sorts of work they have performed, and what sort of recreation they have engaged in, among other things. The development of many of the traits people uncritically take to be “normal” human traits and abilities depends heavily upon the details of how such things are provided. We tend to regard such details as fixed features of our environment. But the fact that a particular environment is *given* to us cannot be understood as providing grounds for supposing that it is “natural.” The environment that has been given to us has also been constructed: it came to have the character it had—and the character it now does—because of prior human decisions to do things one way rather than another. Because particular kinds of institutions were created and particular policies implemented, certain ways of doing things have been reified as norms in our culture, but not, perhaps, in others. And the norms that emerged did so partly because there were even earlier decisions about what human traits it was good to promote, as well as prior determinations of how such things might best be promoted, and of what constituted reasonable trade-offs between competing goods. It is not merely that the features of human environments can differ in ways that profoundly affect what traits humans develop. It is rather that any “natural” human environment must be recognized to be a constructed one and, thus, viewed as a proper object of scrutiny and criticism. The ways we live, the institutions that shape the contours of our lives, and how we see the world are, in a sense, human artifacts, and ones whose implementation is properly an object of moral appraisal.

To say this is not to deny that there are many points of commonality among the different sorts of environments in which humans live, at least if one ascends to a level of suitable generality and speaks in terms of “adequate” food, shelter, nurturance, and so forth. Nor is it to overlook or minimize physical features of the environment or to suppose that all features of environments are mutable. The important thing for us to remember is that while there are many areas of similarity and convergence, and features that may be unchangeable, there are also areas and dimensions of difference and divergence among different cultures and societies, and that there could be even more than there currently happen to be. Thus, even if it were true that humans who fail to measure up to able-bodied standards were disadvantaged not only in our society but in many others, this in itself would provide no justification of our continuing to embrace a human paradigm that accords so much primacy to meeting such standards. (As we have seen, cultures that are less technologically sophisticated might have better reasons for incorporat-

ing such standards.) Nor would it provide grounds for believing that it was disabled individuals' failure to conform to these widely shared standards that accounted for their difficulty or disadvantage: it might explain it, but it would not justify or excuse it.

To see this more clearly, it may help to consider a somewhat artificial parallel. Suppose it were true that females were disadvantaged in many, if not most, societies. From the mere fact of the ubiquity of female disadvantage we could not infer either that the disadvantages women suffer in our own society were to be explained by appeal to some alleged innate deficiency of females or that they were properly understood as stemming from the fact that women just "happened" to make certain sorts of choices: for example, because women were "less rational" than men or "less principled." There are clearly other possibilities worth considering: for example, that in formulating its human paradigm, the society had focused only on a certain segment of the population and largely ignored many others, or that the ubiquity of the belief in female inferiority undercut most women's motivation to try harder to exemplify the (male) human virtues or diminished the likelihood of their being perceived as virtuous (rather than as "unnatural") even if they succeeded in realizing them.

In this imagined world, the women who lived in our society might reasonably demand that we consider the possibility that our society's human paradigm is flawed. Indeed, a human paradigm that attributed "natural inferiority" to such a large portion of the humans who live in that society would seem to be open to the charge of being inadequate in a number of ways. If the society's embracing such a paradigm resulted in its de-emphasizing the value of the things that women did or their entitlement to be supported in the doing of them, or if it rebuffed women's claims of entitlement to equal consideration on the grounds that the things they did and sought to do were not "objectively" important, the society would certainly seem to be vulnerable to the charge of being noninclusive in ways that were both arbitrary and biased: it is only by systematically discounting a large segment of the population that the society could have endorsed a human paradigm that was so heavily male-centered, and it is only by continuing to discount them that it can rationalize continuing to rebuff their claims. Moreover, we recognize that once a society has embraced a certain paradigm, that paradigm is likely to be self-confirming: those who challenge the ways that value is formulated or attributed in that society are thus likely to be seen as railing against the "way of the world" or the "natural order." The fact that a society's evaluations and decisions have colored—and created—what people in that society take to be the way of the world and the fact that the "natural order" is not itself hierarchical may be ones that it is difficult to get people to accept. But—as the example is

meant to suggest—these observations would provide no rebuttal of the claim that the male-centered human paradigm was flawed.

We might say similar things about our own society, and about our continuing to embrace a human paradigm that assigns so much importance to being able-bodied. Clearly, there are a lot of individuals in our society who do not meet able-bodied standards; indeed, there are such a large number that the continued subscription to a human paradigm that assigns so much weight to being able-bodied is exclusionary in ways that should render it suspect.²⁰ We must then consider whether the emergence of such a paradigm reflects the unreasonable exclusion of whole classes of human beings, and whether continuing to embrace it is objectionably exclusionary: whether our uncritical acceptance of it involves both discounting the value of what those who are not able-bodied have done and what they can do, and thus the value and meaning of their lives. If our human paradigm is exclusionary in these ways, it misperceives or misconstrues the achievements of an entire class of individuals and embodies a distorted perception of value, and of the human good. It thus clearly needs to be critically examined. I have suggested that it also needs to be reformulated.

The judgment that someone (or some trait) is abnormal *tout court* reifies the given environments with which we are familiar as ones that are normal for humans and leads us to believe both that disability is illuminatingly understood as a species of abnormality and that the disadvantages that accrue to those we identify as disabled are primarily natural consequences of their abnormality. I have suggested that there are serious problems with viewing things this way. What matters is not simply what is normal, or what is seen as normal, but also how and to what degree the ways we have chosen to live have affected what traits we develop and what we see as normal, and whether our assigning different importance to meeting the needs of those we view as normal and abnormal, or a different meaning to their suffering, are defensible. Our “normal” environments are not exempt from critical examination, and our norms themselves warrant scrutiny. How we live—what we do habitually—even standardly—is not itself immune from assessment and criticism. Whatever truth there might be to the claim that disability is

20. It might be claimed that there are more women—and more able-bodied people—than there are disabled people, and thus that the example is not analogous. I do not know how to ascertain the truth of such a claim. There clearly are lots of ways that people can fail to measure up to able-bodied standards, and, as human life spans lengthen, more people who do now, and more who will do so in the future. I suspect that those who are moved by the difference think something like: it is natural for there to be men and women, for our survival as a species depends on it, whereas it is not natural for there to be able-bodied people and disabled ones. I am skeptical about the force and relevance of such claims, but this is not the place to address them.

a species of abnormality, such a claim would not provide grounds for assigning different meaning to the suffering and disadvantage of those who are disabled, or differential weight to the obligation to meet the needs of the normal and abnormal. The way that a society conducts itself and constructs the lines between normal and the abnormal are clearly proper objects of scrutiny. They should also be candidates for reformulation.

One might be moved to try to blunt the force of these complaints by ascending to a level of greater generality and abstraction and invoking standards of normality and abnormality that are not so demonstrably society-relative, ones that are taken to apply to humans as such, wherever and however they live, and however they might choose to live. I have already explained why we cannot suppose that the ubiquity of a set of practices or beliefs is sufficient defense of continuing to uphold them. But there is another, deeper problem with appeals to “species-wide” norms that we must address.

The attempt to determine what is normal for humans as such is fraught with difficulty. The supposition that we can identify clear, contentful, and univocal measures of environmental normalcy for human beings; the conviction that we can articulate a measure of normalcy for humans that can be omnivorously and disinterestedly applied to all humans in all societies (irrespective of age, race, gender, physical environment, class, and social context); and the presumption that there is a clear metric for assessing the value of different adaptations to non-normal environments are all highly dubious. It may thus be less reasonable to view them as empirically based hypotheses than it is to view them as the expressions of ideology.

The study of history, medicine, and environmental science has made it clear to us that people’s beliefs about the normalcy of their environment are fallible and defeasible. People have often been unaware of features of their “normal” environment that were later shown to be causally critical to the development of conditions that affected their morbidity and morality in serious and systematic ways, and that later came to alter their conception of what constituted a normal environment, and of what they could do to change it. We know, too, that even when people have suspected that there was something amiss in their environment, they have often misidentified the factors that were responsible for maladies, misunderstood the causal relations between various factors, and made alterations to the environment that were insufficient or misguided.²¹ The rise of public health and the refinement

21. It is the force of such explanatory schema—and of our recognition of the need to be open to recognizing the need to reconceptualize the parameters of our problems—that explains why the epidemiological “medical detection” stories of Berton Rouché are so thrilling and engrossing. See, e.g., *Twelve Blue Men* and *The Medical Detectives*.

of the tools of epidemiological investigation have deepened our appreciation of the problems with assessing an environment as normal and have helped us to recognize that what we uncritically reify as “the environment” often consists of parameters that can be altered.

Meditation on the course of recent history also enables us to appreciate how deeply political agendas can color, and skew, people’s views about the normal and the abnormal, and to recognize that we often do not know when our views about normalcy are being manipulated to serve the ends of others. Those who have claimed that individuals of one particular kind are normal and that others who are different in form, stature, or configuration of features are abnormal, deviant, or subhuman have often ignored adaptive considerations, and their “factual” assertions have been both biased and self-serving.²² Whether we think about the rise of the modern eugenics movement, American immigration policy, biological psychology in the early twentieth century—notably, “encyclopedias” and physiognomies of face and form that chose patrician features to exemplify the possession of virtue and ability and the features of immigrants, African Americans, and Jews to exemplify vice and depravity—or the propaganda of the Third Reich, it is clear that the history of relatively recent attempts to isolate and provide a list of traits that are characteristic of “normal” humans and to identify others as abnormal or “defective” provides us with a powerful cautionary tale.²³ Attention to the ways that so many other people’s situated judgments have been fallible, steeped in prejudice, and distorted by the allegiance to dubious “scientific” claims should make us wary of supposing that our views are free from the taint of dubious science and prejudice. Attempts to identify the features of “normal” environments and the range of “normal” human traits are ones I think we would do well to forswear. If we cannot or will not forswear them, then we must learn to be humble and suspicious of those who attempt to attribute any moral significance to the results they “discover.”²⁴

We might hope to avoid the problems I have discussed by abandoning attempts to identify human disabilities as such, and by embracing the narrower and more cautious view that attributions of disability to indi-

22. Thus Jews were stigmatized as grasping because they were moneylenders and caricatured as possessing universally poor eyesight: the former was construed as the sign of an inborn moral failing, the latter as evidence of physical inferiority. The “environmental” facts that Jews were barred from making money in most other ways and often compelled to do close work in bad light were conveniently overlooked.

23. See Daniel J. Kevles, *In the Name of Eugenics* (Cambridge, MA: Harvard University Press, 1995), chap. 9, “False Biology,” 129–47.

24. See R. J. Herrnstein and C. Murray, *The Bell Curve* (New York: Free Press, 1994), for a profoundly flawed “discovery” of race-based genetic inferiority. The book has been widely criticized, especially by geneticists and educators.

viduals are essentially claims about their status within a given society. On this view, assessments of disability are society-based and society-relative claims and thus descriptive statistical claims. However, although it may be easier for us to determine whether something should count as a statistical abnormality in our own society, what we are doing is merely trading one set of intractable problems for another: the greater ease of making assessments of statistical abnormality comes at the cost of a decrease in relevance. It is not clear why the determination that something (or someone) is abnormal in this sense should be thought to be of any particular significance to anyone but statisticians, or why “the way things are in our society” should be thought to provide us with a benchmark that is morally significant.²⁵

It is obvious that not all structural or functional deviations from the norm are significant and that not all statistical anomalies can plausibly be categorized as disabilities. Not all abnormalities are disabling; some are even clearly beneficial.²⁶ And the same “abnormality” does not impact every individual who is adjudged to be abnormal in the same ways. Departures from the statistical norm do not always reduce the quality or duration of the lives of those persons who are correctly adjudged to be statistically abnormal. Nor is it the case that they must decrease the quality of life even when they do decrease it; it may be the society’s failure to cater to those who are statistically abnormal that is principally responsible for the decrease in those persons’ quality of life. For example, it is true that people who are left-handed suffer comparatively more injuries than those who are right-handed and that they tend to live shorter lives. But this stems from the fact that most machines and implements are designed for right-handed persons. And—of course—there are contexts in which being left-handed is advantageous: for example, in some sports.²⁷

25. Manufacturers of clothing and “standard” items might find this information useful. But of course that just raises the question of why it is reasonable (and not just profitable) to be concerned only with the needs of those who are statistically “normal,” and—more generally—reminds us that a society’s economic practices can both “create” disability and exacerbate disadvantage. Even if manufacturers of clothing could not figure out ways to make it “profitable” to make items that fit those who were not “normal,” this is, of course, not the end of the story: why should what is perceived to be profitable to entrepreneurs, investors, and capitalists be the determinant of what should get done? See Harlan Hahn, “Advertising the Acceptably Employable Image: Disability and Capitalism,” in *The Disability Studies Reader*, ed. Lennard J. Davis (New York: Routledge, 1977), 172–86.

26. The link between heterozygosity for the sickle-cell trait and enhanced resistance to malaria is but one instance of many ambiguous “disabilities.”

27. There are relevant differences between being a left-handed hitter in baseball and being a left-handed tennis player. In the former case, it is the design of the game that confers the comparative benefit on left-handed hitters: they are that much closer to first base. In the latter, the advantage consists in the fact that one has a forehand shot where a right-handed person would have a backhand shot.

Moreover, it is often features of a particular individual's environment, class, values, and personality that determine whether the (statistical) abnormality that he or she manifests is a liability or a disability, and how much it disadvantages the individual. The claim that an individual is disabled may thus tell us less about the physiology or physiognomy of the individual than about the society's institutions and the individual's access to resources. It seems reasonable to ask, then, of persons whose deviations from the norm are classified as abnormalities, and whose abnormalities are classified as disabilities, what it is that distinguishes them from individuals who have ostensibly similar abnormalities who are not disabled by them?

There are many human genetic and structural oddities and anomalies that affect individuals for the worse in some ways but affect them for the better in others. There are genetic configurations that result in decreased intelligence, or in social awkwardness, but that are accompanied by augmented powers of recall, great musical talent, or heightened empathy. At least some of the time, such things are not viewed as liabilities by the individuals who are "afflicted" with them, or by those who interact with them. How are such things to be classified? Are these abnormalities that are not disabilities? Are they disabilities for some, but not all, individuals who are "afflicted" with them? What criteria do we use to determine whose abnormality of type *f* is a disability and whose abnormality of type *f* is not?

Such cases are not rare. Their existence calls into question the wisdom of calling upon a human paradigm that assigns primacy to able-bodied standards to try to explain what disability is and what (if anything) is problematical about being disabled. It is far from clear what it is to be able-bodied in the relevant sense—or, more generally, what it is to be normal—and it is not obvious that we can say that not conforming to norms is inherently a bad thing; it is not facts about the individual alone, or about his or her appearance and comparative "functionality," but a richer array of individual, cultural, and economic factors that influences the course of life of those who are not able-bodied and those who are, and of those who are disabled, and those who are not. There is reason to think that much of the suffering and disadvantage of those who do not conform to able-bodied standards—and, more generally, those who are viewed as disabled—arises from the character of their society's interactions with them, or from inequities of class and wealth, and how those affect what sorts of accommodations are available to them.²⁸

Finally, there is reason to question the usefulness of even this shal-

28. Of course, the issues and questions being raised here go far beyond the question of the adequacy of human paradigms that assign primacy to meeting able-bodied standards.

low characterization of disability. It is simply not clear that a condition thought to be a disability must be thought to be statistically unusual. There is no contradiction in supposing that a society might come to have a very large number, even a preponderance, of members who it thought could (or should) be classified as disabled. Consider the plight of (what I shall call) "Obese Society," which some allege is what our society may become in less than a generation. On the assumption that obesity itself is a disability or that it leads to disability, not merely to the stigmatization of obese individuals on cultural and aesthetic grounds, current claims about the "epidemic" of childhood obesity in the United States seem to provide evidence of widespread belief in the intelligibility of the supposition that what we take to be a disability need not be something we also take to be anomalous.²⁹ Those who worry about this epidemic do so precisely because they are concerned about the increase in morbidity and mortality associated with our being obese and, thus, construe obesity as a form of disability or as leading to it.³⁰

It might be objected that our worries about becoming Obese Society do not provide ground for thinking that there can be disabilities that are not statistically anomalous. Indeed, it might even be claimed that the example of Obese Society shows that just the opposite may be true. According to this line of thought, the plausibility of the claim that Obese Society is one in which disability has become the norm stems from the recognition that the circumstances of people in Obese Society are anomalous or abnormal ones. If we lived in Obese World, one in which most people were or had been obese, then we would not regard obesity as a disability or even see it as presenting medical problems. Instead, we would regard the few people who were not obese as we currently regard athletes and dancers, as people possessed of unusually fit and lithe bodies.

I do not think that this objection is telling.³¹ But if it were true that

29. As of this writing, there has been an alteration in proposed medical reimbursement criteria: some weight-loss programs and procedures will now be reimbursable. Interestingly—perhaps surprisingly—the rationale was not that doing so would be a good investment, or a way of decreasing health-care costs, but that being overweight is an illness.

30. The line between disability and ill health clearly is not a bright one.

31. Closer scrutiny of the Obese World scenario will help us see why the objection is not telling. What would life be like for people who are obese in Obese World? It is reasonable to suppose that there would be some salient differences between Obese World and ours. If most people were obese, then life in Obese World would presumably reflect that fact. Neither home life nor social life would be organized around the presumption that individuals could move around a great deal unassisted. There would be less embarrassment and discomfort for obese people, since the entrances to buildings would be easier to negotiate and public transport would have larger seats. The pastimes and entertainments of Obese Society would probably also be quite different from ours: clearly people would probably not be as consumed with sports as we are. Finally, the standards

we use 'disability' to refer to conditions we believe to be statistically anomalous, this might be thought to shed some light on our disability policies. The way that we treat people with disabilities in our society might be connected to our believing that disability is very unusual: being disabled is rare. However, as many commentators have pointed out, this belief is not true. Even if one supposes that a particular condition is to be classified as a disability only if it is thought to be anomalous, there are many conditions that are thought to be disabling: if an individual is viewed as disabled in virtue of his or her possession of one or more disabilities, the class of those who will be counted as disabled will be one that is large, and one whose members are diverse. Once we agglomerate all the individuals whose abnormalities count as disabilities, we may have a very large collection of individuals. It is, I think, more plausible to see people's belief in the rarity of disability not as a belief about the number of individuals who are disabled, but as reflecting their belief that persons with disability are a minority: those who are thought to be in the minority are more likely to be disadvantaged, and the disadvantage is thought to stem from their deviance rather than

of beauty—or even of acceptable appearance—would obviously be different. Would we deny that people in Obese World are disabled? The answer is not obvious; Obese World is seriously underdescribed. It is reasonable to think that life would be better for obese people in many respects in Obese World than it is in ours. But we must ask whether it would also be bad for them in some of the ways that now lead us to view obesity as a disability (or as leading to disability). If obesity were accompanied by a high incidence of diabetes and hypertension, and thus by a high rate of blindness, stroke, organ failure, cardiac problems, serious joint pain, elevated cancer rates, and restricted, painful mobility, then there would seem to be good reason to view it as disabling in Obese World. These illnesses are ones that are painful, frustrating, restricting, and life shortening, and ones we seek to avoid and treat. If obesity had the same sorts of health consequences in Obese World that it does in ours, then it would be reasonable for those in Obese World to regard obesity as problematical and to try to prevent it precisely because of the suffering and pain that it causes. (They might not describe it as disability, but that might have more to do with people's not thinking it pointful to use a particular predicate, especially a "negative" predicate, when they suppose that it applies to almost everyone.) If obesity did not have these untoward consequences in Obese World, then we might not regard it as disabling. But the same might well be true of this world, and of Obese Society: if obesity were not associated with increased morbidity and mortality and increased frustration and pain in our world, it is not clear that we would regard it as a disability. There is no obvious asymmetry here. The Obese World objection thus does not show that we think that disability involves statistical abnormality. Insofar as it has any force, it appears to be merely a reversion to or a restatement of the view that it is not society-relative statistical norms that are important but species-wide norms or species design, or a claim about word use: we do not use 'disability' to describe conditions that we believe afflict most people. This objection was made by Jeff McMahan.

from social practices that exclude them.³² Such a view might provide us with an explanation of many people's attitudes toward disability and persons who are disabled: if they take abnormality to imply rarity, then the resistance to providing more robust accommodation of people with disabilities might stem from the belief that it is only a small portion of people who would be benefited by our so doing or that it is somehow unfair to expect "us" to make sacrifices to benefit "them." But even if we were to suppose that disability is rare and that persons with disabilities were properly viewed as members of a minority, this would not go far in explaining people's attitudes toward disability or disabled persons. It is certainly true that those who are in the minority are more likely to be disadvantaged. But it remains a substantive question whether it is reasonable or just for us to allow those who are in the minority to be treated this way, and what it is that distinguishes those minority groups who have strong claims to better treatment from the majority of those who do not.³³

Subscription to the dominant ideology thus has profound and far-reaching implications. When persons with disabilities are conceptualized as being abnormal, there is a tendency for people to assume that the proper metric for measuring the seriousness—or "size"—of a disability is one that involves an assessment of the degree to which a disabled person is different from a normal one. There is room to question whether there is a coherent measure of disadvantage or disability at work here, but I will not pursue that point. What is more important is that the use of such a metric fails to take account of the quality of life of different individuals who have "the same" disabilities. The viewpoint that it invokes is one that is purely external: it makes no reference to the lived experiences of the individuals it characterizes as having the "same" disability. This is both conceptually and morally problematical.

It is clear, first of all, that not all of those who would be judged by this standard to have the same disability, and thus to be ostensibly equally distant from the norm, are equally affected or "afflicted." Individuals whose passions in life are largely intellectual or cerebral are likely to be less badly affected by a disease or condition that severely limits mo-

32. The view is circular, and unsustainable, but it is clear that something like it informs many people's perceptions; commentators who view disability rights as relevantly like civil rights perpetuate these confusions. See Francis and Silvers, *Americans with Disabilities*, for helpful discussions of how such thinking permeates the ADA.

33. The notion of a "minority" is, of course, neither clear nor unequivocal. Sometimes it is meant to characterize those who constitute a small proportion of the group or population; other times it is used to characterize those who are not members of a favored class. It is only by taking note of both of these uses that one can make sense of claims to the effect that, e.g., the "Hispanic minority" population in California will overtake the White population within the next fifty years.

bility than those whose primary interests are physical or athletic. For example, it is reasonable to think that Stephen Hawking is less severely impacted by having Amyotrophic Lateral Sclerosis (ALS) than someone who had been a professional dancer, tennis player, or pianist would be. We cannot meaningfully calibrate the “size” or seriousness of a disability by trying to ascertain how distant persons with that disability are from the norm, or even how distant we suppose this individual is. We must make reference to an individual’s choices, interests, and values; we cannot merely focus on the “objective” condition of his or her body.

This simple observation may help us see what is problematical about human paradigms that assign primacy to able-bodied standards, and more generally, about those whose standards are purely external, that is, ones that attribute significance to an individual’s possession of public or “objective” properties and accord little or no significance to the character of the individual’s lived experiences. Whether it is distance from the able-bodied standard or failure to exemplify certain specifiable physical properties that is taken to provide the basis of the claim that one deviates from our human paradigm, the problem is the same: the posture is objectionably insensitive, and thus disrespectful. The lived experiences of persons—in this case, of the persons who are being characterized as disabled—are not being accorded any weight.

Moreover, when people invoke an external metric to define or assess a disability, they cannot easily explain the fact that not all people who have (what is ostensibly) “the same” disabilities are equally negatively affected by them. As even a cursory review of discussions of deafness and disability make clear, the inability to explain this fact, or accord sufficient weight to it, has significant consequences.³⁴

The desire to have a clear “objectively” applicable scheme for classifying disabilities is often paired with—or is an expression of—

34. It may be the fact that many people embrace a human paradigm that takes “objective” features to be the determinants or calibrators of disability that accounts both for people’s insistence that we must view all kinds of deafness in the same light, and for failure to appreciate that individuals who are deaf from birth are not necessarily disabled (simply) by their inability to hear. Either deafness is a disability, or it is not. On such a view, the fact that people who live and work in a Deaf environment do not view their inability to hear as disabling might be testimony to the resourcefulness of some deaf people, but it is also properly seen as a form of denial: deafness is a disability. This view is both inaccurate and insensitive: the impact of being deaf can be very different for different individuals. As many commentators have pointed out, deafness is less of an impediment (perhaps no impediment at all) for those who have not experienced hearing loss—particularly if they learn to speak American Sign Language (ASL) early in life—than it is for individuals who lose their hearing in adulthood. The desire to have a clear, physically defined system of classificatory scheme for disabilities often runs roughshod over the salient differences in the character of the lives of those whose disability is “the same.”

subscription to other regulative requirements, most notably the belief that it is scientific and medical personnel who are the proper assessors and appraisers of disability. Because they are presumed to be experts about body form and function, the judgments of medical and scientific personnel are accorded both great credibility and great authority in disability identification and classification. It is medical and scientific personnel whose determinations of disability are informed, and thus thought to be probative. They are thus thought to be the gatekeepers: someone is thought to be classified as disabled only if the relevant experts diagnose him or her as disabled, and it is the experts who will characterize the individual's disability.

The belief that scientific and medical personnel are specially—perhaps uniquely—well qualified to assess disability and should thus be accorded gatekeeper status has some disquieting implications. I will address them in more detail in Section VI. Here it should be noted that the assumption is *prima facie* morally problematical in ways that do not depend upon alleged problems with the particular choice of those who are allowed to exercise such authority. The insistence that one group of people should be entrusted with the characterization of another group of people, and the allegation of the obvious superiority of the “experts” criteria of group membership to those formulated by members of the group in question on the basis of their lived experiences are the epitome of oppression, and perhaps even an ostensive definition of it. Even if we could articulate a coherent “metric of disability,” there is reason to reject its use as a standard.

We have reason to be wary of those who embrace a human paradigm that attributes great significance to able-bodied standards, and—more generally—of those who subscribe to the dominant ideology and thus both characterize disability as a species of abnormality and try to draw normative conclusions from such a characterization. Continuing to embrace a human paradigm that accords primacy to able-bodied standards is problematical in some of the same ways that embracing a human paradigm that accords primacy to the experiences and perceptions of those who are White or those who are male would be: both are objectionably exclusionary. And both involve the assertion of the hegemony of “objective determinants” of a person's status and assign only an ancillary role to the lived experiences of the individuals who are thought to fall outside that human paradigm. I believe that we have reason to be sympathetic to those who call for the critical examination of a human paradigm that attributes so much significance to meeting able-bodied standards and to an ideology that attributes so many of the difficulties that attend disabled persons in this society to their “abnormality.”

III. SOME COROLLARIES OF OUR BELIEF IN THE DOMINANT IDEOLOGY: THE NAIVE CONSTRUCTION OF THE MENTAL AND THE "MYTH OF THE WORLD-TRANSCENDENT WILL"

Reflection on invisible disability can help us understand how subscription to a human paradigm that assigns primacy to being able-bodied—and more generally, to having or manifesting a set of readily perceptible physical properties—is often yoked to or undergirded by subscription to a naive understanding of the mental and the psychological and a simplistic understanding of the relations between mind and body.³⁵ Some of the difficulties that beset uncritical subscription to such a paradigm show up more clearly when we consider illnesses and disabilities that are thought to be principally mental or psychological.

In our society, people's views about mental illness and psychological disorder are often equivocal. On the one hand, it is generally recognized that mental or psychological symptoms can have profound and far-reaching effects. A person who is severely depressed may be unable to sleep or eat; this can result in decreased immunity and serious physical illness. Insofar as people recognize that there is a connection between psychological well-being and physical well-being (more narrowly construed), they are inclined to accord some significance to psychological symptoms, and perhaps not to view them as different in kind from physical symptoms which—if left untreated—would have further deleterious effects.

On the other hand, we tend to assign greater significance and more importance to the manifestation of those mental or psychological symptoms that we take to have identifiable, medically certified physical causes. When no clear physical cause of an individual's psychological or mental symptoms has been identified, people are skeptical and sometimes overtly dismissive: they may question the veracity or reliability of the person who manifests the symptoms. The thinking seems to be that if the relevant medical experts have not been able to identify a physical cause of the mental symptoms, then there is no way that laypersons can distinguish between those individuals who really are afflicted and those who are not: without such certification, there is no way that we can distinguish the person who is really ill or disabled from the person who is dissembling.

The skeptical stance has two components. First, it involves the adoption of a posture of doubt—actually a posture of suspicion—with respect to symptoms that are purely behavioral, that is, those behavioral symp-

35. I shall use "mental" and "psychological" more or less interchangeably, not because I think they mean the same, but because I think that people often use them both to refer to the same phenomena, and in the diagnosis of those phenomena. Sometimes, where context seems to demand it—or license it—I will speak of "behavioral" symptoms.

toms that have not been identified as having a verifiable physical or organic cause. Second, it is characterized by a general reluctance to attach much weight to subjective reports. Since we often rely upon subjective reports to understand and assess behavioral symptoms, the two are connected in practice, although they are conceptually distinct.

What underlies the adoption of this skeptical stance? Why are we so mistrustful? When individuals appear to conform to able-bodied standards, the presumption is that they are “normal” (i.e., not disabled). The presumption can be rebutted, of course: as reflection on the cosmetic surgery example shows, having a body that appears to conform to able-bodied standards is no guarantee of health or functionality. But when it is behavioral or mental symptoms that are the basis of claims of unhealth or disability, the presumption is more difficult to rebut.

At least on the face of it, people’s skepticism might be thought to stem principally from their worries about being deceived by other people, and thus manipulated by them. It is common knowledge that individuals can feign symptoms they do not have and that they sometimes do so to in order to gain some advantage or exemption. And it seems to be especially easy to do this with respect to the sorts of symptoms that are taken to be indicative of psychological dysfunction or mental illness.

That people can report and evince psychological symptoms that they do not have is a truism. We are familiar with stories about criminal defendants who have duped juries by pretending to hear voices, and so forth, in order to substantiate pleas of insanity or mitigate the sentences they would receive if they were convicted of the crimes with which they have been charged. And reminiscences of many of those who were of draft age in the 1970s are replete with reports of elaborate hoaxes perpetrated upon the unsuspecting (and apparently amazingly credulous) officers at their local draft boards in hopes of being granted 4-F status and thus exempted from service in the military.³⁶ Whether such tales are true or merely apocryphal, their point is clear: if we allow that psychological symptoms or “behavior” alone can be the basis upon which we attribute an illness or disability to someone, or that a disability can consist in something other than observable and verifiable physical malfunction, then there is always a possibility that we will be duped by knaves and cheats.

It could be claimed that the desire to deceive others in this way

36. One friend claims to have been granted an exemption by counterfeiting the symptoms of obsessive-compulsive disorder. He studied psychiatry texts prior to his interview and exhibited behavior that he believed his examiners would take to provide compelling evidence of his affliction. The performance was evidently successful: he was granted a 4-F status and thus able to evade military service.

and the ability to pull off a bravura performance in that regard are themselves symptoms of serious dysfunction, even mental illness: perhaps only those who have strong psychopathic tendencies can convincingly portray themselves as psychopaths over a long period of time or be interested in trying to pull off the deception. Though I have some sympathies with those who advance such a view, we need not take a stand on its reasonableness in order to understand or evaluate the plausibility of the skeptical worries about behavioral symptoms. It is not the fact that symptoms are psychological or behavioral that accounts for the ease of counterfeiting them: people can pretend to be experiencing symptoms we regard as physical. Someone can pretend to be unable to bear weight on one foot, claim falsely to have ringing in the ears, deceive us in alleging to have severely reduced sensation in the fingers of the right hand, or pretend to have a stomach ache or a “bad back” to avoid having to perform an unpleasant task.³⁷ Here both our reliance on a human paradigm that assigns primacy to meeting able-bodied standards and the inclination to think that disability involves the obvious deviation from physical standards combine to mislead us. There is nothing uniquely problematical about psychological or mental symptoms. We can be misled in a number of different ways, about a variety of things. The problem that generates the worry lies elsewhere.

The insistence upon the need to be able to verify the truth of an individual's claim to be suffering, in pain, or unable to function in the expected ways, and the assertion that it is only objective physical causes that have been given a medical imprimatur that can provide the needed verification, seem to presuppose the truth of claims that are, in fact, vulnerable to serious challenge. They seem to involve both the wholesale rejection of conceptual and clinical challenges to the adequacy of a purely physical, mechanistic understanding of health and the assumption that we now possess both a complete and an accurate understanding of how the body works and why the body fails. Both of these are problematical.

Even if we were to suppose that all of the things that sicken or disable us will ultimately be shown to have identifiable physical causes, and to claim that these things will thus be shown to be best explained by physical—indeed, bodily—factors, we would have to concede the possibility that there may be illnesses and disabilities whose causes we cannot yet identify. To claim otherwise is to be both arrogant and ignorant. We know that there have been many instances in which medical and scientific experts have been overhasty in their diagnoses—and dis-

37. Insurance companies have also been very effective in getting people to think that this sort of deception is both very widespread and very expensive. It seems reasonable to think people's fears of insurance fraud may exacerbate their suspicions.

missals—of individuals who suffered from symptoms whose physical etiology was not yet known. Chronic Fatigue Syndrome is a valuable case in point.³⁸

But there is a deeper, and more general, lesson to be learned here: there are reasons to reject the view that the things that afflict us, disable us, and make us ill are purely physical in nature, or that they spring from physical causes. There are reasons both to reject narrowly physicalistic notions of health and illness and to resist the view that it is the quest for physically based diagnoses that should govern our understanding of illness, wellness, and disability. We need to acknowledge not merely that blind faith in the complete accuracy and adequacy of current medical diagnoses is misplaced but also that the belief that all departures from health and functionality are ultimately explicable purely in physical terms is both medically and morally problematical. Moreover, even when we think that there is a clear, and clearly identifiable, cause for this person's illness or disability, we understand that the causes do not determine the character of what it is like for this individual to have this illness or disability: "objective" physical causes may shape the character of someone's suffering, but they do not determine it. Even when doctors have robust knowledge about the physical causes of a particular disease or dysfunction, this does not enable them to know what it is like for this individual, now, to suffer from it: there is an irreducibly subjective component of illness, and of suffering and disability more generally. The etiology of suffering is complex: what it is like for a particular person to have a particular malady or disability is affected by his or her psy-

38. Chronic Fatigue Syndrome was dismissed first as factitious, and those who purported to have the symptoms associated with it were dismissed as liars, hysterics, and self-indulgent hypochondriacs. As more and more individuals began to present themselves to doctors with similar symptoms, and as more sophisticated imaging and diagnostic techniques emerged, there was greater willingness to attribute credibility to people who presented with the symptoms of CFS. Nevertheless, many of those who were now conceded to be really ill were castigated for becoming ill. They were seen as bearing some fault for having developed CFS, which was characterized as "the yuppie flu" and regarded as resulting from people's having embraced life choices that were unreasonably demanding; since it afflicted more women than men, and since most sufferers were in their thirties, some commentators suggested that it could be taken as anecdotal evidence of the fact that women who chose both to have families and careers were making unhealthy choices. Finally, when it became clear that it was not just "yuppies" who had symptoms of CFS, and when continued research revealed the existence of symptoms that were not purely behavioral or psychogenic, and identified possible causes of CFS, those who were effectively disabled by CFS were no longer routinely dismissed as fakers or hysterics. Chronic Fatigue Syndrome was recognized as a "real" illness—i.e., one that had real physical causes. There remain significant differences in views about the etiology of CFS. Some see it principally as an "environmental illness"; others see it as an autoimmune response. The two are not, of course, mutually exclusive. This is a reminder that the categorization of illnesses has political dimensions.

chology, by the character of his or her personal relationships, by social and economic circumstances, and by other factors. And the ways that people characterize their experiences and their sufferings—the very ways that they experience pain—are heavily influenced by, if not more robustly determined by, their empirical beliefs, theoretical constructs, and social circumstances. We cannot verify the truth of claims that a person makes about his or her experiences of an illness and may not even be able to assess whether the person's descriptions of his or her symptoms are apt.³⁹

Insofar as those who appeal to the “objective” judgments of doctors and scientists are hoping thereby to eliminate our dependence on the subjective reports of individuals who are ill or disabled, or to be able to gainsay the testimony of individuals who claim to be suffering, their hopes are not only misplaced but also damaging. Such a stance is beset by both scientific and moral problems: we do not know all of the physical causes of illness or of human suffering, we understand that suffering is not purely physical, and we recognize that we need to be wary about asserting that medical professionals' observations about the “objective” soundness of an individual's body should be accorded primacy over the testimony of the person who is (or claims to be) suffering. Because such an assertion systematically discounts the reports and the experiences of the ill person, it both bespeaks callousness and institutionalizes a posture of disrespect.

Moreover, even in purely scientific or diagnostic terms, it is a mistake to suppose that illness or disability can be understood in purely physical terms. Both clinicians and experimentalists acknowledge that illness and disease have psychosomatic dimensions. In many cases, those who are treating an individual cannot understand the illness or its etiology or formulate treatment plans that will be effective unless they make an effort to understand the person's perception of his or her situation and the meaning that he or she attaches to the symptoms. And it is not just understanding the etiology of the illness in this person or formulating an effective treatment plan for him or her that may require the investigation of psychological dimensions. Just as one cannot understand the general without understanding particulars in a clinical context, one cannot understand the particulars without having a more general understanding of illness and wellness. Insofar as we think that doctors should have an interest in promoting health—not just an interest in preventing and curing disease—we have grounds for thinking

39. See Arthur Kleinman, *The Illness Narratives* (New York: Basic, 1988); David B. Morris, *The Culture of Pain* (Berkeley: University of California Press, 1991). For insightful discussion of how cultural beliefs affect the understanding and characterization of illness, see Anne Fadiman, *The Spirit Catches You and You Fall Down* (New York: Noonday, 1997).

that they should be being concerned with (what Arthur Kleinman calls) biopsychosocial factors.⁴⁰ Unless we take note of them, we are unlikely to be able to understand why some people get sick while others do not, why some people who have “the same” disease are far sicker than others, or why “objective” characterizations of a disabling condition can be inadequate guides to understanding an individual’s disability. Far from discounting individual’s subjective reports, some clinicians and researchers present a compelling case for thinking that they can be all-important.

Thus, even if one thinks that the assessments of medical experts should be accorded special significance in matters of illness and wellness, pain and suffering, and disability, this does not give one grounds for thinking the physical assessment of ill or disabled persons is sufficient or definitive, or for supposing that it should be given automatic precedence over the reported experiences of the persons who are ill whenever there is a failure of congruence. There are certainly circumstances in which it would be reasonable to accord precedence to the “view from outside.” But we must at least admit the possibility that there are cases in which such a stance would be unreasonable. It would be unreasonable to decide that a person who professes to suffer from chronic pain is dissembling simply because the person’s physicians—even the “experts” in the field—cannot find a clear physical cause for the pain. Medical knowledge is not complete. And pain is personal, and its etiology complex and multidimensional.

These observations are not especially controversial; indeed some may be simple truisms. I thus believe that the fact that we are so reluctant to accord weight to them should be taken to be a reminder that we can be profoundly affected by presumptions that are unvoiced and unexamined, and as a cautionary tale about what can happen when we continue to rely upon “the standard view”: even when we have compelling evidence that the views are false or overly simplistic, we may still cling to them. We continue to embrace a human paradigm that accords weight to able-bodied standards that have no real connection to health and only a contingent and circumstantial relationship to human well-being. As I see it, our predilection for downplaying the significance of the experiences of individuals who are ill or disabled, and for according great significance to the “objective” medical judgments of third parties, is something that may well be a corollary of our having embraced a human paradigm that accords so much weight to appearances, and to meeting able-bodied standards. If it is, this is another indication that the reliance upon such paradigms may be incompatible with our according proper weight to other elements in our human paradigm, most notably to the recognition that the willingness to accord respect to other

40. Kleinman, *The Illness Narratives*.

persons—and to their experiences—is a critical component of our seeing them as persons.

* * *

In some cases, it is reasonable to suppose that people's inclination to downplay the significance of mental or psychological symptoms stems less from the desire to discount subjective reports and more from views about the will and the nature and extent of individuals' control over their thoughts and feelings. Such views attribute great importance, and great power, to individual volition. In its crudest form, this view embodies what I shall call "the myth of the world-transcendent will": the view that what we think or feel is essentially up to us. Many of those who embrace such a view will probably concede that there are cases in which an individual simply cannot control his or her thoughts or feelings, cases of force majeure in which the person's will has been overborne by physical factors that lie outside of his or her control. But whenever there are no such causes, it is thought, it is reasonable to suppose that individuals can alter their thoughts or feelings. For example, when there are no clearly identifiable physical causes of an individual's feeling extremely anxious or depressed, then his or her continuing to feel that way must be viewed as a matter of choice, or as something that is changeable by decision.

Whether or not it derives from them, this view of the character and extent of individual self-control shares some critical assumptions with the views of Thomas Szasz, whose attack on the legitimacy of the notion of mental illness is well-known.⁴¹ Few people are likely to want to follow Szasz in viewing the delusions of a paranoid schizophrenic as within his or her voluntary control. But many people seem to embrace such a view with respect to other psychological or mental symptoms. Thus, people who are painfully anxious, severely depressed, or immobilized by pain are often seen by others as having succumbed too easily to the challenges and trials of life; they are weak or self-indulgent, not ill: their symptoms are better understood on the model of the hypochondriac's. The way to deal with the misery-producing thoughts, or with the experience of perceived incapacity, is to galvanize the will: to decide to overcome the weakness and just say "no" to feelings of despair and anxiety-generating worries.

Nowhere is there more powerful evidence of people's subscribing to something like the myth of the world-transcendent will than in the oft-expressed opinion that someone who is depressed is not really ill,

41. See Thomas Szasz, *The Myth of Mental Illness* (New York: Hoeber, 1961), *The Meaning of Mind* (Syracuse, NY: Syracuse University Press, 1996), and *Insanity* (Syracuse, NY: Syracuse University Press, 1997).

or not really impaired, because the person could, if he really wanted to, “snap out of it,” or be more cheerful and productive if she would simply try harder to be.⁴² That such a claim is unverifiable, and may often be patently false, is often conveniently overlooked. As many of those who have written about depression have pointed out far more eloquently than I can hope to do, it is a mark of the depth and seriousness of depression that the depressed person is mired in despair and unable to overcome doubts about his or her efficacy. Whether it is false that a severely depressed person could try harder, or true that the person could try harder if he or she really wanted to, but is unable to want to, seems immaterial. And it is clearly irrelevant to assessing the truth of the claim that severe depression can be a disability in and of itself.

Moreover, there is little doubt that some people who are depressed are literally unable to try harder. Those who suffer from depression as a consequence of having sustained mild traumatic brain damage that impaired their frontal lobe have suffered damage to that part of the brain that is thought to be associated with drive and initiative.⁴³ Such persons may be no less correctly characterized as being unable to try harder than those whose optic nerves have been damaged are correctly characterized as being unable to see: in both sorts of case, the individual’s brain has been damaged, and neural connections have been severed. Perhaps they can be repaired, or they can regenerate, or the individual can evolve other ways of accomplishing some of the same functions. But that is not something that willing alone can accomplish. Some commentators—most notably Szasz and those who follow him—would distinguish a person whose depression is the consequence of damage to the frontal lobes, for example, from one whose depression does not result from any identifiable physical trauma to the brain. Both individuals may exhibit the same symptoms, but the former suffers from “a disease of the brain” and is thus properly treated by medical personnel, while the latter is merely experiencing a “problem in living” and is not an appropriate subject of medical treatment. (Indeed, Szasz thinks that medical treatment in such cases is a form of politically motivated indoctrination.)

Even if one believes that differences in the etiology of depression can themselves be thought to provide grounds for differential diagnosis, this does not justify the claim that there should be differences in treat-

42. In *Why Zebras Don’t Get Ulcers*, Sapolsky calls readers’ attention to ‘John Henryism,’ a term invented by Sherman James, an epidemiologist at the University of Michigan, which “involves the belief that any and all demands can be vanquished, so long as you work hard enough” (332). See also Sapolsky, “The Burden of Being Burden-Free,” in *The Trouble with Testosterone*, 137–46.

43. See Elkhonen Goldberg, *The Executive Brain: Frontal Lobes and the Civilized Mind* (New York: Oxford University Press, 2001).

ment, or in social response. Nor is it reasonable to insist that two people should receive differential disability assessments on the basis of the etiological differences alone. A depression that is rooted in a person's experiences and perceptions is not necessarily accompanied by different observable behavioral symptoms or different neurochemical changes, nor must it be subjectively different from a depression that has been caused by a brain injury in which there has been damage to the frontal lobe.⁴⁴ Either can make an individual acutely miserable and unable to function. Whether depression stems from a brain injury or is instead thought to be psychogenic also has no clear implications for treatment: both "sorts" of depression are likely to be most effectively treated by medication and therapy, and, in some circumstances, each kind may be effectively untreatable, and thus perhaps permanently disabling. Depression is depression. It is sometimes seriously disabling and effectively incurable. It is sometimes successfully treatable in the course of a couple of months, though successful treatment often takes longer. But however it is to be classified, it is not its etiology per se, but its impact on the person who is depressed that must be viewed as significant.⁴⁵

I have tried to show not merely that there are internal problems with human paradigms that assign primacy to able-bodied standards and with the dominant ideology but also that subscription to such a human paradigm and endorsement of this ideology may rest on foundations that are morally and psychologically suspect, and ones that have normative and theoretical implications that are disquieting. Because I believe that the problems with our continuing to embrace such views are neither recondite nor obscure, I believe that we must dig deeper and ask why it is that we continue to embrace views that are so woefully inadequate, and so clearly inhumane. Though I cannot present a detailed argument for the view in this article, I believe that there is reason to suspect that many of the prevailing attitudes toward persons with disabilities, and the social policies that express those attitudes, are buttressed by our culture's encouragement and reinforcement of the adop-

44. Ibid.

45. Nor does it depend on the presence or determination of (what is popularly characterized as) "neurotransmitter imbalance." The interaction among, and balance between, neurotransmitters is complex: there are many different ways that they may be unbalanced. Relatedly, different sorts of medications are likely to be effective for different people, and the supposition that one can arrive at independent determinations of "the correct" imbalance and assessments of the effectiveness of a particular sort of medication is not well-founded. Finally, even in a case in which the relevant medical professionals could not find any neurotransmitter imbalance in a particular individual, (a) treatment might be beneficial and (b) we would not hesitate to classify the person as depressed (and if sufficiently dysfunctional, as disabled). See David Healy, *Let Them Eat Prozac* (New York: New York University Press, 2004), and *The Creation of Psychopharmacology* (Cambridge, MA: Harvard University Press, 2002).

tion of a deforming posture of denial. In the sections that follow, I will offer some explanation and defense of this claim.

IV. INVISIBILITY

Our pretheoretical understanding of the notion of invisibility in the social context has been shaped by the iconography of comic book superheroes, and by our culture's absorption of insights from the work of such diverse writers as Hans Christian Anderson, H. G. Wells, and Ralph Ellison.⁴⁶ Initially, we might think that the invisible should be characterized as that which is unseen, or (in some cases) unseeable. (H. G. Wells's invisible man was, when completely unclothed, both of these things.) But as I pointed out above, what is unseeable to us here and now may not be unseeable to us in other contexts, and what is unseeable by us is not therefore imperceptible. Although humans tend to accord primacy to vision as a means of acquiring knowledge of the external world, we know that we cannot infer nonexistence from invisibility: what is unseen by humans, and even what is unseeable by them, is not therefore nonexistent or even necessarily imperceptible. Wells's invisible man was not visible to other people, but he was clearly real, and indeed, painfully so; once aware of his predicament, people could both infer his presence and "see" where he was. Whether someone's invisibility is the product of a science experiment, a gift of the gods, or the expression of a social policy, invisibility is (at best) a mixed blessing: it may confer benefits and special privileges, but it also removes one from the public world and reduces the possibility of personal interaction. For an embodied social being, to be invisible is to live in an equivocal state. Being invisible—or believing oneself to be—can foment a dreadful conflict between a person's own perception of him- or herself and the perceptions of others. To be real yet invisible to others is to live in a permanent state of conflict and to be clawed by irresolvable uncertainty.

Ellison invoked invisibility as a metaphor for social exclusion: a way of characterizing the anger-edged isolation people feel when they are marginalized, or socially discounted, because they are perceived to be different in ways taken to mark them as inferior. By reflecting on the predicament of Ellison's protagonist, we can arrive at a fuller understanding of the complexities of the normative dimensions of invisibility.

Ellison's protagonist was certainly fully visible to many human perceivers—notably, to himself, and to other Black people.⁴⁷ And he was

46. Hans Christian Anderson, "The Emperor's New Clothes" (1837); H. G. Wells, *The Invisible Man* (1900); Ralph Ellison, *Invisible Man* (1952).

47. But the complications deepen and multiply here, since it is common for those in oppressed groups unconsciously to adopt the perspective of the oppressor and, thus, to see themselves from the perspective of the oppressor.

not of course, literally invisible to White members of the society. He was undeniably present, but since being White was taken to be a necessary condition of being morally considerable, he was excluded: he did not count. It was not simply that Blacks were found wanting when measured against the society's human paradigm; it was rather that they were ruled out *a priori*. In referring to himself as an "invisible man," Ellison's protagonist meant to be calling attention not only to the *de facto* marginalization of Black people but also to the fact that the society's accepted standards of normalcy, social standing, and visibility were ones that were not simply natural, or ones that could be justified by appeal to facts or features that were uncontroversial and relevant. Rather, the standards were applied rigidly and imposed callously: they were deployed even when the consequences of doing so could be shown to be damaging to those who did not fit the human paradigm, and—as Ellison made brilliantly clear—even when they were damaging to the society as a whole.

In contemporary society—by that I mean roughly that of Middle America in the early twenty-first century—it is the perspective of those who meet able-bodied standards that is privileged. Those who fail to conform to those standards are not literally invisible, but they are marginalized: they are socially invisible. In saying this, I do not mean to be suggesting that being disabled is "just like" being Black or to be claiming that the social exclusion of persons with disabilities should be thought to be just like social exclusion based on race or gender. My intention is merely to underscore points I have been arguing for throughout the article.

It is likely to seem to those who are members of a given society that their society's human paradigm and correlative notions of normalcy make reference to or draw upon obvious and natural empirical facts that can be asserted to be self-evidently relevant. But a consideration of the observations of Ellison's narrator should make us recognize that it is a mistake to assume that this is the case. Neither the truth of the alleged facts nor their relevance is likely to be self-evident to members of the society whose appearance marks them as abnormal—and inferior—by the society's lights. And even when there is broad general agreement about what the facts are, facts do not speak for themselves. The society decides which facts will be accorded relevance, and which of the relevant sorts of facts about persons will be accorded greatest importance and embedded in its institutions and evaluations. And even in ostensibly democratic societies, not all voices have equal volume. Since being White was taken to be a necessary condition of exemplifying the human paradigm in the society of Ellison's narrator, it is not surprising either that the Whites in that society were obsessively preoccupied with the (alleged) objective, observable differences between Black

persons and White ones, or that they were concerned to emphasize the gap between Whites and Blacks. By emphasizing the gap, Whites could overlook relevant similarities and misdiagnose and misconstrue the etiology of obvious differences: in a society that denied education, decent housing, and employment to Black people because they were Black, it is not surprising that Blacks would be viewed as “uneducated and lazy.” This was problematical not merely because it was viewed as a reason for according less attention to the experiences of Black persons than to their facial differences from White persons, thus both institutionalizing injustice and ignoring harm. As Ellison makes clear, these practices also harmed Whites and damaged the larger society of which both Blacks and Whites were a part.

It should not be thought that I am asserting the existence of a perfect parallel between the social invisibility of disabled persons and the social invisibility of Blacks in the time of Jim Crow. There are salient logical differences here as well as the critical historical ones. Those who were White could reasonably expect that they would not become Black in the course of their lives; they could thus rely on the fact that a system of White privilege would be beneficial to them both now and later, even if it was harmful to Blacks. But those who now meet able-bodied standards cannot maintain that a system of able-bodied, or even “ableist,” privilege will benefit them. In statistical terms, illness, injury, accident, or infirmity beset most of us. And the longer we live, the greater are the odds that we will live some portion of our lives as disabled persons. (In numerical terms alone, the odds that we will all be related or closely connected to someone who is disabled are overwhelming.) In continuing to advocate—or even tolerate—our society’s subscription to a human paradigm that marginalizes disabled persons, and a dominant ideology that pathologizes them, we not only harm those whom we now marginalize but also do something that threatens to make our own lives go less well by our own lights. If our society continues to marginalize and devalue those who are disabled, then it is likely that most of us will face marginalization. We will thus both be devalued by others and come to see ourselves as less worthy, less valuable, or less than fully human simply in virtue of our becoming disabled.

It would clearly be beneficial for us to try to effect a change in how disability is viewed in our society. Though perceptions may seem to be less amenable to alteration than policies, the way that we see things is not “natural” or immutable. As Hans Christian Anderson reminded us in “The Emperor’s New Clothes,” human perception and human volition are often tightly bound. Our perceptions—both who and what we see and who and what we do not see—are not merely socially mediated, they are also volition-sensitive. Something may be invisible to us not simply because we habitually focus our attention elsewhere or because

we are expected to look elsewhere, but because we have been taught not to see what is in front of us or to acknowledge that sort of thing. Once we have been socialized to do as others do, we come to see as others see. This is neither a simple inability to see, nor a simple failure to pay attention, but is, in fact, a sort of volition-mediated blindness: we have been taught not to pay attention to or not to acknowledge what we see. It may not be true that there are none so blind as those who will not see. But it is reasonable to hope that those who have been taught not to look—or not to see—can be taught to do otherwise.

However, we need to recognize that some of the people who are socially invisible have not had invisibility conferred upon them simply because they belong to a class that has been traditionally overlooked in our society. It is not always simply habit or history that are at issue. Individuals can be marginalized not merely because those of us who possess socially favored status are self-absorbed or habitually or deliberately inattentive, but also because we actively (though not consciously) employ defensive strategies to protect ourselves from having to acknowledge realities that are frightening or unpleasant. Clearly, we need to look beneath the surface. In recent years, both people with disabilities and disability rights advocates have done a lot to make it clear how people with disabilities have been marginalized. They have undertaken to explain how the continued marginalization leads not only to injustice but also to the acceptance of policies that are immoral and self-defeating. But although things have gotten much better in some respects, they still have not changed radically: persons with disabilities continue to be stigmatized and disadvantaged. To understand why there is still so much resistance to adopting more inclusive practices and policies, it is not enough to rehearse the arguments for fuller, more sensitive policies of inclusion or rebut the arguments against them. We need to delve into the deeper causes of people's continuing to marginalize those they see as disabled and to examine why they continue to resist conclusions of arguments they cannot rebut.

There is so much fear of aging and infirmity in our society, and so much stigma attached to being disabled, that the prospect of being disabled seems terrifying to many of those who see and present themselves as able-bodied persons. When something is terrifying enough, people seek to protect themselves by distancing themselves from it. This is not a startling observation, nor is it an indictment of our concern for self-protection. Indeed, historically, the marginalization of those who visibly failed to meet able-bodied standards is not hard to understand: it is a practice that might have had survival value in earlier phases of human history (see Sec. II). Before humans had a scientific understanding of disease processes, and before they lacked effective ways of preventing, curing, or even treating most diseases, individuals' failures to

meet able-bodied standards might have been taken to be signifiers of the presence of transmissible disease. If so, then both attempts to limit one's interaction with such individuals and the endorsement of practices that marginalized them might have made good sense.

But even if the marginalization of the disabled can be rationalized as having once made good sense for humans in earlier periods of human history, that rationalization no longer holds: it clearly does not work here and now, in our society. We now have much greater understanding of the causes of disease, and we are able to perform complex and sophisticated diagnoses to distinguish between communicable diseases and noncommunicable ones. Both the duration of human lives and the conditions in which we live and work have changed radically. Even if—as is not obviously the case—there were other no other grounds for renouncing it, these things undercut the reasonableness of invoking any such rationale.

Drawing upon Ellison's *Invisible Man*, we can see how the price of our continuing to marginalize individuals who are disabled is high not only for those who are marginalized, or even for those who will be marginalized. By continuing to magnify the distance between themselves and persons with disabilities, people who are in the grip of a human paradigm that accords primacy to meeting able-bodied standards may pay a steep price. They may avoid confronting (and making peace with) the human vulnerabilities that both unite all of us and shape the character and the quality of our lives: the limitations that result from our embodiment as living beings in human form.

Even if we are lucky enough to escape disability, stigmatization, and marginalization, we are likely to know, love, and work with people who experience such things. Both in order to relate to them in meaningful ways and to empathize with them we must seek common ground. Our common ground lies in the need for us to acknowledge that, as human moral agents, we are both vulnerable, and limited, and to recognize that it is the presumption—and understanding—of this common ground that helps give content to the value we ascribe to respecting others. For human beings, the recognition of vulnerability involves the acknowledgment that even the best-ordered, most well thought-out, and deeply considered life plans can be derailed by things that lie outside of our control, and the acknowledgment that our lives may not be seen as good by other people even when we succeed in living lives that are good by our own lights. Because this sort of discordance is intensely painful, we have reason to want our practices and institutions to acknowledge its possibility and help mitigate its effects. And this should give us reason to favor a human paradigm that is more inclusive rather than less inclusive, and one that accords weight to the experiences of persons themselves, and not just to external standards of evaluation.

Here again, the moral and the psychological intersect and reconnect in a multitude of ways. To the extent that a human moral agent cannot (or will not) contemplate the implications of his or her frailty and finitude, that agent risks alienation from other people. If we do not come to terms with our own human vulnerability, we are unlikely to have a deep understanding of the notions of loss, risk, suffering, or grief or to understand the causes of vanity, envy, jealousy, or resentment in others. Thus, if we deny our own frailty, we are likely to have a diminished appreciation of others' humanity and unlikely to be able to have a sympathetic understanding of, or engagement with, other people's triumphs and defeats. This is both personal and moral impoverishment: our lives go less well, and they are less good.

No rational human can believe himself or herself to be invulnerable. Martha Nussbaum states the point with characteristic elegance: "Human beings are born into a world that they have not made and do not control."⁴⁸ Nor can we plausibly believe that it is merely our own choices and actions that determine either the shape of our lives or their character. However prudent a person is, however learned, however virtuous, he or she is sometimes powerless to prevent the sort of damage, suffering, illness, injury, or infirmity that can, in an instant, diminish the scope of what is possible within the compass of that life. The failure to acknowledge and accept these things is, it seems to me, akin to a refusal to be bound by the laws of physics: it is not merely a form of stubbornness, it is also a deep form of irrationality that can beget a terrible immorality, one that leaves one less able to avoid initiating dangerous deeds and making self-defeating choices. Individuals who do not acknowledge and accept the limits imposed by the facts of human physical and psychic vulnerability are more likely to stumble through their lives recklessly, and thus more likely to cause great damage both to themselves and to other people. The attempt to understand and accept human vulnerability would thus seem to be a prerequisite both of our being able to formulate rational life plans and a precondition of our succeeding in living lives we see as valuable. Our society's human paradigm should reflect some understanding of these things—or at least provide a testament to the importance of our continuing to grapple with them. To the extent that we embrace policies predicated upon the marginalization of those who are (now) disabled, those who live in our society do something that is neither rationally nor morally defensible: it is something that may undermine our own efficacy as moral agents, our understanding of ourselves, and our capacity to perceive and appreciate value.

48. Martha C. Nussbaum, *Hiding from Humanity: Disgust, Shame, and the Law* (Princeton, NJ: Princeton University Press, 2004), 177.

I have argued that the failure to confront issues about human vulnerability is likely to result in damage to ourselves and injury to others. But some people may be unmoved by my analysis of the impoverishment of living an unenlightened life, or by my prognostications of the dangers in so doing. And some may think it is better for people to ignore these sorts of dangers and to turn away from sorrow: we should live our lives boldly and hope for the best. Such individuals may be unpersuaded by the revelation that this is a risky strategy and a reckless one and reject the claim that their good will be furthered by the pursuit of disabled persons' good. I think that reflection on the society chronicled by Ellison should give them pause. Even if one can be confident of not being marginalized, a society that emphasized visible, superficial differences between people is more likely to be one in which many people are thwarted in the pursuit of deeper good. However, even those who are unmoved by this observation or by the call to simple prudence cannot claim to be justified in continuing to support the marginalization of disabled persons or condoning their exclusion from the heart of our society. You may wish to avoid having to think about unpleasant things and to live your life in glorious oblivion. But the fact that it might be annoying—or even painful—for you to have to acknowledge persons who are disabled or to interact with them in person-respecting ways provides you with no grounds for assigning less value to persons who are disabled, or less weight to their needs and interests. It thus does not excuse the endorsement of, or acquiescence in, policies that severely compromise the well-being of persons with disabilities. Even if the reminder of the causal complexity of self-interest or the call to decency fails, recognition of the universality of the desire for respect and the force of claims of justice should suffice.

My main concern in this section has been to call attention to the fact that how we see others and assign social status to them—the ways that we make judgments of comparative significance and of value—are both socially mediated and volition-sensitive, in multidimensional and complex ways. But what should we do with this information? We might begin by resolving to pay more attention, and by making a conscious effort to interrogate judgments to the effect that something is “natural” or to the assertion that the differential weight we attribute to the claims of *a*'s and *b*'s stems from verifiable, significant, and relevant differences between *a*'s and *b*'s rather than from unexamined, possibly indefensible policies that unjustly discriminate between *a*'s and *b*'s or merely thinly rationalize dubious practices.

Still, as reflection on the problems attending the myth of the world-transcendent will should remind us, we must recognize that simply making attempts to “try harder” are likely to be ineffective and insufficient by themselves. It is often possible to come to see things that were for-

merly invisible simply by learning where to look and how to attend more carefully: a large part of becoming a naturalist is learning how to look more carefully at the natural environment so that one can see more of the activity in an ordinary field than one could before. But heightened attention alone may be insufficient: sometimes we need to try to recalibrate our sensibilities before we can hope to be able to expand our sphere of vision by reeducating our senses. In the case of social phenomena, this recalibration and reeducation may involve a species of what used to be called, in the context of trying to increase feminist awareness, “consciousness-raising.” And it may be that it is by reading literature, rather than just science and social science, that we are most likely to effect it. But whatever we call the process, it is clear that we need to recognize that there is always habit, and sometimes many kinds of subtle choice, involved in human perception, and in our characterizations of some human conditions as more “natural” or more “normal” than others. We need to recognize this before we can hope to be able to tease out the silent presuppositions that underlie our subscription to a human paradigm that accords so much weight to able-bodied standards, and through which we see and characterize—and do not see—disabled persons. And we must learn that we can, and must, critically question the validity and significance of those characterizations. One of Ellison’s principal insights—and gifts to us—was to remind us that our failures of perception can be deeper and more systematic than we suppose and that they can constitute a deep form of irrationality and a very deep moral failing. The failure to recognize that we are in denial can lead us to reify our habitual blindness as part of the given: it can become so deeply ingrained that some persons literally cannot see what is, for those who are being marginalized, blindingly real. The effects to both can be disastrous.

V. DISABILITY

It is clear that persons with disabilities that are visible—a vague characterization that I will take to pick out the sorts of disabilities that are readily apparent to other persons in a “garden-variety” interaction like, for example, a trip to Target to buy batteries, underwear, and cat food—are often socially invisible. Even when they share the same space with them, able-bodied people often do not look at or interact with persons they see as disabled or do not treat them as full persons. We live in a society in which there has often been tacit collaboration to avoid granting access to disabled persons or to avoid acknowledging their presence even when they are undeniably physically present, and one in which people are not generally aware of the fact that their behavior is exclusionary. We have already seen that the roots of (what I will henceforth refer to as) practices of exclusion are tangled, and they run deep. In

part, the practices of exclusion become social customs or habits, and they are passed on from one generation to another. Parents often instruct young children to refrain from doing things like staring at “the nice person in the wheelchair.” This is something that is seen as a matter of courtesy, or good manners, and it appears often to develop quite seamlessly into the familiar “tactful” adult practice of averting one’s gaze from those one perceives as disabled and blossoms into the sort of disrespect manifested, for example, by a waiter’s insistence upon speaking about a (lipreading) deaf person or a wheelchair-bound individual in the third person, rather than directly addressing him or her. At some point, though, what is customary, or standard practice, becomes willful disregard and discourtesy. It is not polite to pretend not to notice salient facts about other people, especially when one’s doing so causes embarrassment or inconvenience to them. Nor is it polite to treat adults like children.

The passage of the ADA has enabled many disabled people to gain greater access to public places. And by mandating the mainstreaming of many disabled children in public schools, recent disability laws have helped to increase the presence and visibility of disabled persons of all ages. There is also little doubt that debates surrounding the proper interpretation and implementation of the ADA and criticisms raised by individuals associated with Disability Rights movements have also helped to raise public consciousness about disability issues and about both the extent, and the character, of society’s prior blindness to them.⁴⁹ However, even if we concede that those who live in our society now nominally recognize that it is indefensible to turn away from people with disabilities, ignore them, or treat them in ways that are blatantly discriminatory, it can be argued that the defensiveness and denial implicit in our continued commitment to a human paradigm that accords so much importance to meeting able-bodied standards help to perpetuate a deeper, more insidious, and more damaging denial of the humanity of disabled persons.

As a society, we have failed to recognize that the very patterns of contemporary American life and the institutions that sustain it often discount or exclude disabled persons and, thus, effectively remove them from the public domain. We have modified our architecture to enable some disabled persons to have greater access to public buildings and

49. Litigation has been helpful both in clarifying the ADA and in getting people both to think about what it is that is “disabling” about disability. In this regard, the ADA’s stance with respect to obesity is particularly revealing: although overweight people are often stigmatized and excluded both from public spaces and semiprivate ones, only those persons who are 100 percent above the weight that is normative for their height are candidates for a disability designation. See especially Mary Crossley, “Impairment and Embodiment,” in Francis and Silvers, *Americans with Disabilities*, 111–23.

have made changes that enable some persons with disabilities to be physically present and reasonably safe in the workplace and the classroom. But persons with disabilities have not received the sort of global social acceptance and accommodation as disabled persons that is needed for them to be (or try effectively to be) happy, productive, and successful. What this makes clear is that we need to recognize that there is another, more obvious and arguably more serious way in which many persons with disabilities remain invisible: in large numbers, they are often absent from the public realm.

Making physical changes that ease ingress, egress, and mobility in an environment enables only a narrow range of persons with disabilities to participate as full members of society. Partly because we tend to understand being disabled in narrow terms and to see it primarily as consisting in, or caused by, the failure to meet able-bodied standards, we as a society have focused much of our attention on making (some sorts of) material changes in the environment that facilitate the participation of those who appear to us to be disabled, that is, those who do not meet able-bodied standards. That is, of course, not a bad thing in itself. What is problematical is that we have not addressed the presuppositions that underlie our adoption of our standard *modus operandi*. We have thus failed to recognize that there are many more subtle and pervasive mechanisms of inaccessibility and exclusion that may both exacerbate disability and limit the participation of disabled persons in the life of the society. This observation applies both to those whose disabilities are visible and to those with invisible disabilities: to those who clearly do not meet able-bodied standards and to those who meet them but are nevertheless disabled, that is, to those who have what I have characterized as invisible disabilities. But—as we shall see—it is particularly powerful when applied to those with invisible disabilities.

A fairly obvious and mundane example is illustrative here. The way that the workweek and the workday are configured and paced can present obstacles to the presence and participation of disabled persons that are no less formidable than limited physical access to the workplace. Consider a diabetic, a person with rheumatoid arthritis, a person with multiple prostheses, a person who has CFS, and a person who has sustained an MTBI in an automobile accident and is in recovery. All of these individuals are likely to be unable to work for long blocks of time without taking breaks. The diabetic must be able to stop to monitor glucose and to eat frequent meals, that is, to eat after shorter intervals than “normal” people do. People with severe hypertension and CFS must avoid high-stress situations and get a lot of rest. Those who are recovering from MTBI must avoid stress, and they may be painfully sensitive to noise and light. People with multiple prostheses or arthritic conditions may be unable to work at the pace, or in the position, that

others do. If society does not compel employers to make appropriate accommodations, then employees with these disabilities may not be able to continue to work for those employers. These employees are thus more likely to become unemployed and to disappear from the workplace. They will thus become invisible in the most dramatic and important sense: they will be absent from the social world.

In addition to the details of temporal pacing and institutional organization, there are more pervasive, less obvious features of the social environment that can provide formidable obstacles, impediments, and deterrents to people with disabilities. As Susan Wendell has pointed out, the fact that our food, essential personal items, and household goods tend to be sold in supermarkets, which are huge, largely windowless unventilated boxy spaces with blindingly bright lights, miles of aisles, and lots of hard shiny surfaces that lack places for people to sit down in the middle of a shopping trip to collect their wits or simply to rest for a few minutes, effectively restricts access or provides a powerful deterrent to many people with disabilities.⁵⁰ Such an environment is unfriendly, unhealthy, and sometimes overtly dangerous to people who, for example, have fibromyalgia, panic disorders, severe attentional deficits, degenerative joint diseases, or MTBI. Since this is so, such individuals often avoid the supermarket altogether. They are thus perfectly invisible: they are altogether absent from the public sphere. Moreover, because these disabled people are absent, those people who do frequent these places may erroneously suppose that there are few individuals who are in predicaments like theirs and thereby unwittingly do things that contribute to the increased marginalization of those who are already marginalized. Furthermore, because the absence of people with invisible disabilities can lead others to underestimate the urgency of the need for us to contemplate changes in the way that social services are provided and our basic institutions are configured, it can function as a disincentive even to think about making those sorts of changes: in this case, to think about changing the way that supermarkets are arranged. When people are out of sight, they are usually out of mind. It is thus easy to underestimate the number of people with disabilities or fail to appreciate the acuteness of some of the socially mediated—and potentially remediable—problems of individuals with disabilities.⁵¹

50. Susan Wendell, *The Rejected Body* (New York: Routledge, 1996).

51. This phenomenon is similar to the restaurant ramp problem: as a number of people have reported, when restaurant owners whose premises are not accessible to people in wheelchairs are told that they would have more customers if their restaurants were wheelchair accessible, they have been known to remark that they do not see much need to modify their premises because they do not have many "handicapped" patrons. The idea that there might be a strong connection between the absence of people in wheelchairs and the inaccessibility of their premises seems not to occur to them.

In fact, the problem is both more complicated and more serious than this. When people with disabilities like the ones I have just cataloged do venture forth into what they reasonably perceive as a hostile environment, they often try to camouflage their disabilities. Since those who are perceived as disabled are generally stigmatized, people whose disabilities are invisible are understandably reluctant to identify themselves as disabled. Moreover, because those whose disabilities are invisible are often subject to interrogation about whether they are “really” disabled, the price of revealing that one is disabled can both seem and be quite high. I will discuss this problem further in the next section. The point that is most relevant here is that the revelation of one’s disability often accomplishes nothing. Beyond the provision of ramps and wheelchair accessible bathrooms, there are often no mechanisms of accommodation for people with disabilities. Where there are no mechanisms of accommodation, it is reasonable to suppose accommodation is not forthcoming, or that—if it is—it will be of the noblesse oblige variety. And where this is so, individuals with disabilities may believe both that they will be stigmatized if they articulate their needs or call for assistance and that they will not receive the assistance they need.⁵² So, if they visit such places, they are likely simply to struggle and to suffer in silence; their problems thus go unnoticed.

People who are not disabled may not recognize that something as basic as the configuration of the supermarket plays a role in making the lives of some disabled persons worse, or that it is directly implicated in forcing disabled persons to make difficult trade-offs. If a trip to acquire batteries, cat food, and underwear—something that is a mundane errand for most nondisabled people—is an exhausting running of the gauntlet for persons with the disabilities I have just mentioned, then persons with disabilities face difficult choices and may often be forced to make imprudent trade-offs. For them, a trip to the supermarket may not only be an unpleasant experience, it may also have a very high opportunity cost: it may preclude the possibility of their being able to do much else. It may thus exacerbate the individuals’ disabilities and deepen their invisibility. By failing to consider the high cost of their participating in public life and indirectly encouraging their absence from the supermarket, we may visit upon persons with disabilities the ultimate form of invisibility. By not taking account of the people whose disabilities are not obvious or cannot be accommodated merely by mak-

52. And from whom could they request assistance? In supermarkets and general stores like Target, it is hard enough for those who are not disabled to find anyone who is both knowledgeable and obliging. Even if the prospects of success are no lower for disabled persons than for those who are not disabled, the transaction costs are likely to be much higher.

ing physical alterations in the avenues of ingress and egress, we do something that increases not only the misery of people who are disabled but also the extent of their disability. Clearly this is self-defeating. Insofar as it can be conceptualized as a failure to prevent preventable suffering, it may also be immoral.

There are several points we should take note of here. First, the way that disability is characterized within the human paradigm that we embrace leads us to overlook, ignore, or deny the existence of disabilities that are not readily apparent to us. It may thus lead to our engaging unwittingly in policies of exclusion that render the lives of disabled persons more difficult. Second, if we do not have a mechanism in place for identifying nonobvious disability, it is likely to be unclear what, if anything, we can do to mitigate its damaging and isolating effects. But if nothing is done, then persons with conditions that are restricting but nonobvious are likely to be underrepresented in the public sphere. Third, we are thus likely to underestimate the number of persons with disabilities, the seriousness of their circumstances, and the urgency of their needs. We are thus likely to underestimate the importance of meeting the *prima facie* obligation to mitigate the unnecessary suffering of disabled persons, both those whose disabilities are visible and those whose disabilities are invisible: those whose needs cannot be accommodated simply by making “obvious” physical alterations in the structures of ingress and egress, but only by making more sweeping changes in the environment.

If we embrace a human paradigm that attributes great importance to meeting able-bodied standards, we may be inclined to view the alteration of social expectations in narrow, largely linear terms: if we change our expectations, then we must be either raising them or lowering them. If being able-bodied is taken to be normal, it is pretty clear how such a change in expectations would be viewed. But such a view of things conceals the fact that in making the social world more accessible to persons with disabilities what we are doing is recognizing the richness and diversity of the human good, the multiplicity of the ways in which it can be attained, and the unduly restrictive consequences of our previous *modus vivendi*. This hardly constitutes a lowering of expectations. There are people who believe that imposing “restrictions” on the way we live our public lives and conduct our business unduly limits human freedom (i.e., the freedom of those humans who are business owners and entrepreneurs). But it is the assignment of priority to “economic freedom” at the expense of the promotion of greater inclusion that needs defense. As a number of commentators have pointed out, “business as usual” is responsible both for causing much

disability and for undervaluing the human misery thus produced.⁵³ Those who would view the adoption of more inclusive practices of accommodation of disabled persons as a lowering of standards because it would be “unfriendly to private enterprise” or damaging to “the bottom line” need to be reminded that damage to the economy is not *ipso facto* damage to the society. And it is a society we live in, not just an economy.

VI. INVISIBLE DISABILITY

I have tried to explain how a closer look at persons with invisible disabilities—and at the notion of invisible disability itself—can help us uncover some of the problems with a human paradigm that accords primary importance to being able-bodied. So that we can have examples in mind, I will (in a brief and perfunctory way) mention some examples of what it is that I take to be “invisible disabilities.”

I take invisible disabilities to include painful or limiting conditions that meet any or all of the following conditions.

1. Neither their presence nor their nature can usually be ascertained in the course of the completion of a mundane social interaction—for example, a trip to Target to buy batteries, cat food, and underwear. Obviously, this will include a wide range of things. Among them are severely impaired hearing or restricted vision, Crohn’s disease, severe hypertension, degenerative joint disease, serious fibromyalgia, and some mental illnesses. What unifies these—very different—disabling conditions is that the existence or nature of the disability in question cannot generally be ascertained by someone who is merely looking at the disabled person or engaging in limited and nonstrenuous interactions with him or her, like conversing in a checkout line.
2. They place the individual at a heightened risk for the recurrence of episodes that would be painful, life threatening, or activity limiting. Again, this will include a wide variety of conditions, including severe allergies to things that are encountered in the everyday world (bee stings, common household goods or perfumes, peanuts, or dairy products), partially manageable seizure disorder, and chronic hypertension.
3. They severely limit the duration or the circumstances in which the individual can interact with other persons in everyday social spheres. Among the many different things that fall under this description are fibromyalgia, CFS, anxiety-panic disorders, chronic migraine, MTBI, and degenerative joint disease.
4. Their presence can be verified by technical medical procedures

53. Harlan Hahn argues convincingly that our economic institutions have both swelled the ranks of the disabled and greatly reduced the quality of life for those who are not “acceptably employable” (Hahn, “Advertising the Acceptably Employable Image”).

or blood or microscopic assay and their identification is both straightforward and uncontroversial: for example, diabetes, Crohn's disease, and severe hypertension.

5. They can be diagnosed by medical personnel, but their identification or classification is not purely quantitative but involves interpretation and requires the use of judgment. Again, the range of things that may fall under this description is very large, and examples are intended merely to be illustrative: anxiety-panic disorders, depression, MTBI, posttraumatic stress disorder (PTSD), chronic pain, and some cognitive deficits.

In some respects, the things that I have identified as invisible disabilities are congruent with commonsense notions of disability. People recognize that there can be conditions of mind and body that can impair an individual either by causing that individual pain or great discomfort, or by making it exceedingly difficult for him or her to meet basic social and personal needs, yet not be perceived by others in the course of regular personal interactions. The visibility or invisibility of a disability is something that is determined by the ease of its perception by others, not by its impact on the persons with the disabilities. But in arguing for the inclusion of invisible disabilities within the category of disability, and persons with invisible disabilities within the extension of disabled persons, I am not merely arguing for an expansion of the class of individual referents to whom the term 'disabled person' may be—or should be—applied. I think that reflection on the explanations of the inadequacy of the social response to those who have invisible disabilities gives us good reason to suspect that our commonsense notion of disability itself is fundamentally flawed. Effecting the conceptual repair or reinterpretation that is needed is likely to involve a major overhaul: it has the potential to alter our understanding of what it is to be disabled, to affect our views about personal identity, to precipitate a reconsideration of the role of normative presumptions in our assessments of human wellness and infirmity, and to ring changes in other, seemingly unrelated areas of social policy. Obviously I cannot spell out these connections and implications in detail here. What I will try to do is give an indication of some of the ways that the inclusion of invisible disabilities calls our human paradigm into question and casts doubt on the notion of disability that is associated with that paradigm.

When we think about invisible disabilities, we can better appreciate something that many disability rights advocates believe to be true, and something that I have tried to explain: the determination of whether an individual human is disabled is not based purely on the biological, anatomical, or functional properties that can be attributed to the in-

dividual as such.⁵⁴ It makes essential—if often tacit—reference to the cultural and institutional context in which the individual is located or embedded and the sorts of expectations that the context generates. “Context” of course is vague. It includes the physical environment and makes reference to norms and variables that are economic, social, and class-, gender-, and age-related.⁵⁵

Closely connected to this is a challenge to another presumption of the interpretation of disability that emerges from the adoption of a human paradigm that assigns primacy to meeting able-bodied standards and is reflected in what I have called the dominant ideology. Although it is widely rejected by disability rights advocates and has been attacked by many commentators, the received view still seems to be that the possession of a disability is something that is objective and a verifiable matter of fact.⁵⁶ It is thus thought to be something whose existence can be easily perceived, and whose presence can (and perhaps must) be verified by the consensus of the relevant experts, who are generally thought to be medical experts. But these assumptions are unfounded, as we can see by considering individuals who suffer from chronic pain, varieties of CFS, fibromyalgia, severe anxiety, or clinical depression. In most or all of these cases, there is no set of well-defined, objectively identifiable physical factors or bodily changes that can be identified as “causing” the symptoms that contribute to or comprise the disabling conditions. Clearly, clinical depression can be disabling, and severe chronic pain of long duration probably always is. Both to understand how they are disabling and what the suffering of individuals who have these conditions consists in and to diagnose and characterize the disorder, we must make reference to the lived experience of the persons who have the symptoms.

Because their disabilities are invisible in the ways I have described,

54. See David Wasserman, “Philosophical Issues in the Definition and Social Response to Disability,” in *Handbook of Disability Studies*, ed. Gary L. Albrecht, Katherine D. Seelman, and Michael Bury (Thousand Oaks, CA: Sage, 2001), 219–51, for a useful overview of the position and its rationale.

55. When different sorts of occupations are normative for people in different social classes, genders, or ages, one individual’s inability to do *x*, or to do *x* without significant difficulty, pain, risk of damage, or undermining of the possibility of doing other things necessary for self-preservation, may constitute an impediment and be seen as reflecting a disability or infirmity, while another person’s inability to do *x* without incurring those costs would not be. Much may also depend on how fluid the social roles are.

56. Again, it is often worries about the potential “abuse” of a disability characterization that seem to drive many of those who embrace such a view: unless it is an “objective matter of fact” that someone is disabled, the fear is that there will be many unscrupulous fakes and malingerers who will “take advantage” of a disability characterization. That such a view betrays both a serious lack of imagination and a lamentable lack of empathy has been pointed out.

a person with an invisible disability must often point out the existence of his or her disability to other people. This can be an awkward and thoroughly unpleasant undertaking, especially in a society in which “tact” is often interpreted as compelling able-bodied persons to refrain from attending to, or commenting on, perceived disability, and one in which people both shun and stigmatize persons they see as disabled as a defense against having to confront their own vulnerability.⁵⁷ It should thus be recognized that people whose disabilities are invisible are regularly put in the position of having to challenge the adequacy of our society’s human paradigm head on, and of having to confront the wall of denial that surrounds and upholds our subscription to this paradigm. In many cases, revealing one’s invisible disability to others involves a running of the gauntlet. Because human paradigms that accord so much significance to being able-bodied encourage us to exaggerate the difference between persons who are able-bodied and those who are not—and thus the difference between being disabled and nondisabled—those who meet able-bodied standards often suppose that the difference between themselves and anyone who is disabled must be obvious. When someone looks like a nondisabled person but claims to be disabled, this is jarring: it presents a challenge to the adequacy of this human paradigm.

In order to receive needed assistance or accommodation, someone whose disability is invisible must usually both reveal the fact of disability to other people and provide information about the disability in question. As I pointed out in Section III, the revelation of invisible disability can often be greeted with a skepticism that can be both difficult and painful to dispel. Since it is impossible for most laypersons to verify the truth or falsity of many claims of invisible disability, an interlocutor’s willingness to believe that the individual has an invisible disability may be contingent on his or her willingness to assume that the person is both credible and informed. Because pointing out to others that one has a disability that is invisible both challenges the soundness of their understanding of disability and threatens to erode their defenses, interlocutors may make stringent demands on a person who professes to have invisible disabilities. It is not enough simply to provide such interrogators with information. What they want is proof.

However, it is not merely proof, and it is not simply proof. Often what able-bodied interlocutors seek is not simply information that explains the disability or evidence that suggests that the invisibly disabled person has been honest in the provision of that information. Even when

57. Nussbaum, *Hiding from Humanity*, 219: “Normals know that their bodies are frail and vulnerable, but when they can stigmatize the physically disabled, they feel a lot better about their own human weakness.”

they are willing to revisit received views of what disability consists in, able-bodied interlocutors may still want to be able to invoke a standard that enables them to reassert the existence of a fundamental difference between themselves and persons they classify as disabled. This may help explain why persons with invisible disabilities are asked for medical certification so often. The provision of medical certification not only categorizes and reifies the disability, it also helps reestablish psychic distance between the able-bodied person and the person who is disabled. In focusing on the details of the other person's disability, able-bodied interlocutors can—at least to some degree—minimize their personal engagement with the disabled person who stands before them and seeks their aid.

As I noted above, the psychic costs to people who have invisible disabilities can be very high. Those whose disabilities are invisible may be pressed to reveal the sort of details about their personal medical history that most of us regard as private, and as humiliating to expose. Since those whose disabilities are invisible are not seen as disabled persons, their success in being classified as disabled—and thus accorded whatever accommodations they need—may require the revelation of a good deal of information that is intensely personal, as well as the revisiting of circumstances that may have been traumatic. Someone who has sustained a closed head injury in the course of a sexual assault may be pressed to reveal details about her life that others are allowed to keep to themselves and may be compelled, in effect, to relive the assault. As I have tried to explain, the intensity of pressure to provide the information cannot always be explained as stemming from the need for interlocutors to know what they should do to help, as it might be thought to be in the case, for example, of someone who is diabetic. Because people with invisible disabilities appear to meet able-bodied standards, they are viewed as able-bodied: they “pass.” Moreover, because they have passed, the revelation of their disability may seem, at some level, to be the revelation of prior deceit. The fact that it is the presumptions of nondisabled able-bodied persons that were ungrounded and not the conduct of invisibly disabled persons that was untoward is easy for those who are steeped in our human paradigm, and in the dominant ideology, to overlook.

Revealing that one has an invisible disability is thus, in some respects, like “coming out of the closet.” The invisibly disabled person is not viewed simply as providing neutral information, but as providing startling information, and information that contradicts the beliefs of those to whom it is being revealed. He or she may thus be met with incredulity and anger. The incredulity could take the form of others' experiencing an epiphany and revising their unexamined views about disability, and about what is involved in viewing a person as disabled.

Some people, when confronted with the news that a good friend is gay, may quickly and silently revise their unfavorable stereotypes about homosexuality and not feel threatened or unsettled in the process. But this sort of response is rare. As is often the case when a person reveals his or her homosexuality, an interlocutor's willingness (or ability) to accept the truth of the individual's declaration of (invisible) disability may be contingent on the provision of more information and verification.⁵⁸

The skepticism that confronts a person with an invisible disability is thus deep and multidimensional. When someone's disability is visible, people may feel no need to raise the question of whether the person really is disabled and no need to challenge the claim that he or she is disabled.⁵⁹ Because the possession of disability is stigmatized, those who are thought to be obviously disabled are thought to be "different." For reasons we have already explored, nondisabled persons are prone both to exaggerate the degree of the difference between themselves and persons with disabilities and to suppose that—because there is such a big gap between them and disabled persons—if someone is disabled, it will be obvious. People with invisible disabilities are thus often put in the position of having to rebut the presumption of "normalcy."

When someone's disability is invisible, the difference between disabled persons and nondisabled persons is not so obvious; indeed, most of those who interact with a person who is invisibly disabled may never know that they have done so. The revelation of an invisible disability may thus be felt as an assault on the reasonableness of the interlocutor's attitudes and paradigms: the interlocutor's response may thus be defensive. Moreover, because people whose disabilities are invisible are thought to be well-positioned to feign disability—something they might wish to do to "cheat" the system—in order to cancel the presumption that the invisibly disabled person's able-bodied appearance is the person's lived reality, he or she must provide not only information to an ill-informed general public but also provide testimony. To provide testimony that is seen as credible, it is often not enough for someone to provide information about the disability or explain what it is like for him or her to live from day to day. Persons with invisible disabilities must often be able to adduce evidence, often in the form of appeals to the judgment of the relevant experts. Because of the predominance accorded to medical models of disability, and the authority accorded to medical professionals to be gatekeepers of the social designation of

58. I do not want to overemphasize the similarities. But I see clear parallels between people's insistence on being told how someone "knows" that he or she is "really" gay and their insistence on being provided with some proof that he or she is really disabled.

59. As I pointed out in Sec. III, this common assumption is problematical: it is possible to fake both visible and invisible disabilities.

disability, people often view doctors and medical diagnoses as the only truly credible authorities: in practice, it is doctors who are viewed as final arbiters of disability. By itself, and in its own terms, the testimony of the witness-victim—the invisibly disabled person—is not probative.⁶⁰

Even if the invisibly disabled person is viewed as a sort of expert witness, his or her situation is untenable. In our society, providing expert testimony is a tricky business. Both people who have had personal experience with the courts and those who have merely observed their operations on television are likely to believe that there can be duly certified experts who are crackpots and experts whose conclusions may be reasonably suspected to be something less than objective and disinterested.⁶¹ And when the etiology of the illness or dysfunction is not well understood, there is likely to be disagreement about both its proper diagnosis and its cause, even among those who are thought to be the relevant experts. Because people may already be somewhat cynical in their assessment of the force of expert testimony, unless there is a solid consensus among doctors that the invisible, putatively disabling condition really is disabling, and accepted medical “proof” that the invisibly disabled person really “has” the disability, there may well be resistance to the suggestion that the invisibly disabled person should be counted as disabled. Although the problem can arise both for those whose disabilities are visible (or noninvisible) as well as for those whose disabilities are invisible, it clearly is much more likely to arise in the latter case and to be more intractable when it does arise for a number of reasons: the ostensive “normalcy” of the invisibly disabled person’s appearance is more likely to be taken as providing counterevidence to his or her claim of disability. When the testimony of the medical “experts” does not provide solid support for the claim of disability—which is not a rare occurrence—persons with disabilities that are invisible may thus be unable to meet the burden of proof. Once again, we have the ingredients of oppression: both the judgments of observers and the opinions of

60. It is problematical, of course, to view the invisibly disabled person as either a witness or a victim: disability is not a crime. This is yet another reason to think that an interlocutor’s adoption of an interrogative stance is objectionable and that our continued social tolerance of such practices is profoundly damaging to persons with invisible disabilities.

61. In the former category might be thought to be those “pro-life” physicians who offered opinions about Terri Schiavo’s mental capacity without conducting their own examination of her; in the latter are “experts” who have, and do not reveal that they have, significant conflicts of interest (e.g., physicians who are also investors in pharmaceutical companies that provide them with handsome “incentives” to prescribe their drugs). How much the popularity of television dramas that have reenactments of trials (and of Court TV that shows “the real thing”) has done to increase people’s sophistication about such things is not clear. What is clear is that such shows have contributed appreciably to people’s perception that they understand the court system.

privileged experts are allowed to carry more weight than the statements, and even the painful revelations, of the disabled person.

As I have argued, the problems here run very deep. There are many (invisible) disabilities whose presence is not straightforwardly “objectively” determinable or provable in the relevant ways. An individual may suffer from clinical depression or have an anxiety disorder or chronic pain, for which there are no “objective” causal correlates. These diagnoses are made on the basis of symptoms, and the symptoms are ones that make essential reference to the individual’s behavior and to the character of his or her experience. A diagnosis of chronic pain, for example, may depend heavily on the presumption of the truthfulness of the person who reports his or her experiences: here there is no possibility of making an “objective” diagnosis that disregards, or is independent of, the person’s reported experiences. Nor is the process of diagnosing an objective one; it is not only experts’ medical knowledge but also their personal and political attitudes that may color their interpretation of the meaning of the symptoms and, thus, influence the choice of diagnosis. As we have seen in reflecting on the evolution of attitudes toward CFS, there are times when the experts may discount patients’ narratives rather than take account of them. And even when they attribute credibility to their patients, “medical experts” who have clear views about what it is appropriate for people of a certain age or gender to do—or try to do—may see their patients’ symptoms as self-caused. When confronted with a patient who is obviously haggard and losing weight, few physicians are likely to doubt the truth of the patient’s reports of the inability to sleep and eat. But if a woman reports (and evinces) these symptoms in a context in which she is struggling with harassment or overt gender discrimination on the job, for example, a “traditional” physician may view the patient’s depression and anxiety as essentially self-caused: as stemming from the patent foolishness of thinking that she could do a “man’s job,” and as evidence of the inappropriateness of her choice to try to do so.⁶² Particularly in cases in which a “medical expert” has a strong social agenda or a clear bias, the line between viewing a person’s symptoms as self-caused and disbelieving their reports of their symptoms is unclear. By forcing persons with invisible disabilities to seek a medical imprimatur and to provide one to

62. What it is that even a traditionalist views as a “man’s job” will of course change over time. Women who are just now entering the labor force may be surprised to learn that that characterization was applied to a much larger number of things thirty years ago. By the lights of a physician in the student health services of a large distinguished university, it was the inappropriateness of a woman’s pursuit of an academic career (and higher degree) in mathematics, and not the hostile environment of the exclusively male mathematics, that “explained” her depression and misery (JH, personal communication).

interlocutors before they can make a legitimate claim of disability, we may be holding them hostage.

Even when they are not unsympathetic, not all doctors are equally informed, especially about more recent medical phenomena.⁶³ In the early 1990s, symptoms routinely associated with MTBI—impairment of memory and executive function, depression, heightened anxiety, and subtle changes in personality—were seen as psychosomatic by general practitioners not acquainted with the research on the effects of acceleration-deceleration injuries on the frontal lobe.⁶⁴ And even when there is progress, not all of the experts will agree: medical experts are embodied human beings who may have political points of view that are unacknowledged or unexamined, and imperfect comprehension of the changes at the frontiers of medicine.⁶⁵ Since medical experts are also members of our society, it is not unreasonable to suspect that they too may have assimilated some of the dubious empirical beliefs that underlie our human paradigm and the dominant ideology that informs it. According them gatekeeper status with respect to the reality of invisible disabilities is institutionalizing a posture of disrespect.

Those with invisible disabilities may thus find themselves in a position that is both difficult and painful. Because they appear to meet able-bodied standards, they must rebut the presupposition that they are “normal,” that is, not disabled. The presumption that there are deep and obvious differences between being “normal” and being disabled is one that is deeply and dogmatically held: it is taken to be self-evident. Because of this, it may not be easy for persons with invisible disabilities to rebut the presumption that they are “normal”; it may not be sufficient for them to assert that they are disabled or even to provide detailed information about their condition and the narrative of its etiology. Though they may be pressed to reveal information that is both personal and private—and perhaps deeply upsetting—the revelation of this information may not be thought to constitute sufficient proof. Because they seem to meet able-bodied standards, the revelation of disability produces a dissonance: to rebut the challenge that they are lying, they are often pressed to provide “real” medical evidence of their disability.

63. As I have pointed out, fifteen years ago CFS and related conditions were not regarded as real illnesses, but as ones that were essentially psychogenic in origin; subsequent research has revealed the presence of pathogens thought to cause the illness. See also Wendell, *The Rejected Body*.

64. Goldberg, *The Executive Brain*.

65. For good discussions of some of the problems physicians may face in acquiring timely and unbiased information about medical—particularly pharmacological—advances, see Marcia Angell, *The Truth about the Drug Companies* (New York: Random House, 2004), chap. 8; and John Abramson, *Overdosed America* (New York: HarperCollins, 2004), chap. 8.

When their condition is “new” or ill understood, or the evidence is equivocal (because the experts do not agree), persons with invisible disabilities may also have to undercut the suspicion that their symptoms are hysterical. Thus, even if they are acquitted of the charge of simple lying, they may have to be able to rebut the challenge that they are overreacting. In the case of psychological symptoms or disabilities—or ones that have a psychological tinge—there is often another layer. As we saw in the case of a depressed patient whose workplace constitutes a hostile environment for people of that gender or race, even when such people are believed, they may be chided either for being foolish enough to continue to work in that environment, or for not trying hard enough to overcome the disabling conditions. People with depression, anxiety disorder, and the complex of symptoms associated with recovering from MTBI can attest to the misery and frustration involved in having to do this. It is not hard to see how it could be infuriating to have to do it in order to receive necessary accommodation.

The challenge to provide convincing proof can be both onerous and practically insurmountable. Invisibly disabled people often face variants of (what I shall call) “the handicapped parking space challenge,” which provides a clear and succinct illustration of the difficulties of having to face (and overcome) this challenge. When those who have an invisible disability exercise one of the “perks” of having been granted official, medically sanctioned recognition of their status as disabled and park in one of the spaces designated for disabled persons, they are often confronted by righteous citizens who feel entitled to play a vigilante role. As many can attest, when people with invisible disabilities park in a “handicapped” parking space, they may be accosted by strangers who feel entitled to quiz them about why they are parking there, since they are “obviously not handicapped.” Because they appear to meet able-bodied standards, people with invisible disabilities are seen as “normal”; because they appear to be normal, members of the general public may suspect that they are “cheating” by parking in spaces that are designated for the use of “handicapped” individuals even when they have the appropriate tags or stickers prominently displayed on their cars. They are thus seen as seeking to be granted special privileges rather than exercising a right, as seeking an unfair advantage rather than trying to level the playing field. Those who have found themselves in this situation know that there is often no comfortable resolution to it: they are hard-pressed to reveal personal details to hostile interrogators who may have no ability to assess the accuracy of those details. Telling these interrogators that one’s personal circumstances are none of their business is seldom effective; indeed, it can escalate the confrontation, which merely

exacerbates the discomfort of those whose claim of (invisible) disability is being challenged.⁶⁶

It is also profoundly counterproductive to be repeatedly exposed to hostile challenges. Many conditions are far more activity restricting, far more unpleasant, and potentially far more health compromising when a person is forced to dwell on his or her symptoms and pushed into exaggerating them, or merely having constantly to attend to them. Headaches are often like this; chronic pain is, so is anxiety. To “prove” that they are disabled, those with invisible disabilities are often compelled to focus attention on their problems. But doing this can exacerbate the problems, intensify their suffering, and augment their disability. The costs of our continuing to embrace a human paradigm that assigns so much importance to meeting able-bodied standards and our continuing to subscribe to the dominant ideology that underlies it can be very high indeed for disabled persons.

Clearly, it is damaging for persons with invisible disabilities to have to shoulder the extra burden of trying to teach others about their condition and having to rebut the able-bodied paradigm’s presumption that “what you see is what you get.” Even when people succeed in making their case, thus proving to others’ satisfaction that they are disabled, what they may have is—at best—a Pyrrhic victory. They may be able to lay claim to the “special” services that they need to function in our society. But in being perceived as people who need these services or accommodations, they are likely to be more prominently marked by the stigma that attaches to being designated as disabled. This, of course, provides considerable disincentive. Those whose disabilities are invisible will often have more motivation to “pass” than to “come out,” which may imperil their well-being, exacerbate their disability, and deepen their invisibility.

* * *

I have tried to show how reflection on the difficulties faced by persons with invisible disabilities can help us achieve a deeper appreciation of how the prevailing understanding of disability is deeply flawed. Insofar as that understanding can be seen as deriving from, or connected to, our subscription to a human paradigm that accords primacy to meeting able-bodied standards, and to our embracing something like the dominant ideology, I have argued that it is conceptually confused. Both the recognition that there are disabilities that are invisible and the acknowledgment that many of the people who are disabled have disabilities that are invisible pose a challenge to the moral defensibility of

66. I wish to thank members of the Boulder Women’s Brain-Injury Support Group for sharing their parking miseries with me.

our unreflective views about ability and disability, and to the intelligibility and moral defensibility of the human paradigm that seems to underlie them. If we leave our human paradigm unexamined and unchallenged, I have argued, we have good grounds for believing that we will have a deficient—and defective—understanding not just of disability, but of the human condition.

I have also tried to show how our continued subscription to a human paradigm that assigns primacy to meeting able-bodied standards renders us more likely to choose and follow paths that both undercut other of our publicly professed values and may lead to our living lives that are less good by our own lights. But recognizing these things is only half the battle. The conceptual and moral defects in our “commonsense” views about ability and disability bespeak a profound psychic disconnection on our part, one whose continuation might be thought to expose the moral failings of cowardice and lack of integration. If we hope to be able to live lives that are truly good by our own lights, we must address the sources of our psychic disconnection and seek both to uncover and understand some of our deepest—and potentially profoundly damaging—anxieties. By considering how our “commonsense” views about disability can be understood as representations (or embodiments) of our anxieties about acknowledging our own mortality and frailty, we might hope to be able to gain deeper insight into why we stigmatize those whom we perceive as disabled, and why we resist the view that people who look “just like us” may nevertheless be disabled. It is my hope that the recognition that persons who are disabled are not (as such) ones who are “abnormal” or “other” in some radical, palpable, and objectively verifiable way may help pave the way toward a more compassionate view of persons with disabilities, and of ourselves as embodied human beings.

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